Australian & NZ Cerebral Palsy Strategy

2020

Contributing Authors

Australian and New Zealand Cerebral Palsy Strategy Collaboration

A collaboration consisting of representatives from cerebral palsy organisations and consumer representatives from Australia and New Zealand.

Lead organisations

Ability First Australia is a not-for-profit strategic alliance between 14 of Australia's leading disability service providers, with member organisations in all states and territories. Our members have a long and trusted history, having supported people with disability for between 50 and 85 years.
https://abilityfirstaustralia.org.au

Cerebral Palsy Alliance is an international pioneer in research into cerebral palsy and is a leading not for profit organisation committed to providing world-class services for people living with a broad range of disability and their families.
https://www.cerebralpalsy.org.au

Cerebral Palsy Australia is the national peak body of organisations that work with people with cerebral palsy as well as people with similar disabilities and their carers.
https://cpaustralia.com.au

The Australasian Academy of Cerebral Palsy and Developmental Medicine is a multidisciplinary professional academy that provides scientific education for health professionals and promotes research and high-quality clinical care standards for people with cerebral palsy and developmental conditions.
https://ausacpdm.org.au

The Cerebral Palsy Society of New Zealand aims to enhance the lives and well-being of people with cerebral palsy in New Zealand by empowering them to make their own choices. Through its membership, the Society offers practical everyday programs and awards grants for people with cerebral palsy to enable access to items of service that assist in promoting independence and quality of life.
http://www.cerebralpalsy.org.nz

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Acknowledgements

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An Expert Panel of professionals and key influencers in the field of cerebral palsy provided additional consultation throughout development and drafting of The Strategy. These individuals were invaluable in providing a breadth of stakeholder perspectives.

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- Centre of Research Excellence in Cerebral Palsy
- Cerebral Palsy Alliance
- Cerebral Palsy Education Centre
- Cerebral Palsy Support Network
- Kids Rehab WA
- Victorian Paediatric Rehabilitation Service
- New Zealand Cerebral Palsy Register
- Australian Cerebral Palsy Register
- New South Wales and Australian Capital Territory Cerebral Palsy Register
- Northern Territory Cerebral Palsy Register
- Queensland Cerebral Palsy Register
- South Australian Cerebral Palsy Register
- Tasmanian Cerebral Palsy Register
- Victorian Cerebral Palsy Register
- Western Australian Register of Developmental Anomalies – Cerebral Palsy

Community Consultation

The Strategy Collaboration would like to thank all members of the cerebral palsy community who contributed their valuable input through participating in community consultation. Special thanks to Shannon Clough and Shirley Wong who contributed countless hours representing the cerebral palsy community as part of the Strategy Collaboration. We would also like to thank Chrissie Cowan (Kāpō Māori Aotearoa Inc. New Zealand), June Riemer (First Peoples Disability Network Australia) and all those who contributed quotations and photos to be featured in The Strategy.

Please note, quotes included in the Strategy were obtained through community consultation and are therefore not necessarily reflective of the opinions of the individuals featured in photos.

Foreword

Cerebral palsy is the most common physical disability in childhood. In Australia alone, it is estimated that there are around 40,000 people living with cerebral palsy. The recent announcement of the declining rate and severity of cerebral palsy in Australia demonstrates that work to reveal the various causes of cerebral palsy and implementation of preventative strategies is working. However, people living with cerebral palsy still experience significant barriers in everyday life .

The Honourable Dame Quentin Bryce together with Shannon Clough and her son Ethan

The time is right for an Australian and New Zealand Cerebral Palsy Strategy, to build on the momentum of research success, and advocate for the needs of people with cerebral palsy and their families. Particularly in the era of the Australian National Disability Insurance Scheme and similar programs in New Zealand, a unified voice, clearly articulating areas of unmet need for people with cerebral palsy is an important step to catalyse change across the disability landscape.

Although the initial plan was to develop a specific Strategy for cerebral palsy research, we realised that research does not sit in isolation, and much more could be achieved by developing a comprehensive strategy for the field. Thus, the mission of the Australian and New Zealand Cerebral Palsy Strategy is to achieve a more inclusive and accessible society. To do this, The Strategy aims to improve the health, function, participation and quality of life of individuals with cerebral palsy and their families. As such, The Strategy provides a framework which outlines key priority areas for the field of cerebral palsy; highlighting areas of unmet need that will be used to inform key decision makers and guide action to deliver improved healthcare provision and disability support, promote excellence in research and enhance community knowledge.

Proudly, The Strategy is informed by people with cerebral palsy, their families, health professionals and researchers working in the field of cerebral palsy across Australia and New Zealand, and delivery of this document would not have been possible without the collaboration and support of various disability service provider and advocacy organisations across Australia and New Zealand, as well as numerous individuals who provided their expert advice, and participated in the consultation process.

Buoyed by examples of other National Strategies that have delivered significant impact for their respective fields, such as the National Asthma Strategy, HeartKids Australia's White Paper on Congenital Heart Disease and Cancer Australia's strategic plan, it is our hope that The Strategy will be a tool to build collaborative networks to act on identified priority areas, and leverage viable and sustainable funding avenues through clear articulation of objectives.

We acknowledge that this current version of The Strategy is by no means a final, perfect product. It is designed to be a living document that will undergo multiple revisions over time. We therefore put forward this document as an initial plan that can be built upon, and we welcome and encourage other contributors to help refine and improve the document, to ensure that it is a Strategy for all people impacted by cerebral palsy.

Quentin Bryce.

The Honourable Dame Quentin Bryce AD CVO

Foreword

As a person with cerebral palsy I am really pleased to endorse this new Australian and New Zealand Cerebral Palsy Strategy. This is a great opportunity for the empowerment of people with cerebral palsy, particularly as the Strategy acknowledges that society has an important role to play in terms of inclusion and equality. I am sure many people with cerebral palsy will appreciate that the social model of disability is so central to the Strategy's design.

Every day, people with cerebral palsy are constrained by limited accessibility and low expectations about what they can achieve in their lives. The Strategy provides a roadmap to address these. Of course, abolishing these types of barriers benefits not only people with cerebral palsy, but the whole community.

I was born with cerebral palsy and because I'm 50 years old now I consider my disability to be a small part of who I am as a person. I don't want to get rid of it because is all part of my normality. I live a full life within the community, have my own place, work full time as a community program manager and have the same aspirations in life as everyone else. In spite of all of this, many strangers look at me like an alien to keep away from, a person to treat like a minor and someone who will achieve nothing in his life. There is still much to do before people with cerebral palsy achieve true equality.

The social model of disability is paramount in regard to the lives of people with cerebral palsy, as it assumes that the main driver of exclusion is society, not the person. I'm confident that in the future medicine will be able to reduce, if not eliminate, any impairment we may have. This will certainly change our views of diversity and disability in society. Until we get to that point, we need to focus on the social model by eliminating barriers and limitations and celebrating this type of diversity in humanity.

The Australian and New Zealand Cerebral Palsy Strategy provides the foundation for our generation to address the social issues described above, rather than leaving them to the next generation to deal with. Its implementation will help us build a society where everyone has the same opportunities to thrive and be recognised as equal.

Chris

Christian Astourian

Foreword

A fundamental obstacle to disabled people experiencing equitable health and social outcomes is not having opportunities to fully participate in decisions that affect us. This means supports and services may not reflect what is most important to us, nor be provided in accessible places or ways. Invisibility can result in a lack of investment, and inflexible or inadequate supports can create further obstacles to education, to gaining or sustaining employment - which in turn affects many choices that impact on quality of life, such as housing and participation.

So, strategies that impact on the lives of disabled people must be grounded in the voices of the people they intend to benefit. The Australian and New Zealand Cerebral Palsy Strategy is clearly a living example of "the nothing about us, without us" approach.

Complex issues can only be addressed through collaboration. This Strategy demonstrates the kind of collaboration required between all stakeholders, most importantly people with cerebral palsy, advocates and communities, practitioners across the health system and between government agencies.

This Strategy reflects a social model of disability, and the need to respond to the interaction of disability, inaccessible environments and disabling attitudes. It clearly sets out the challenges people living with cerebral palsy face, their priorities, and what is required for people to live the lives they want to lead. It provides direction for making significant and positive change.

It is congruent and consistent with a wellbeing focus and a human rights approach and provides a comprehensive overview of current evidence and thinking in the field of cerebral palsy advocacy. Furthermore, this document seeks to inform key decision makers about unmet needs of individuals and their families, thereby improving inclusion, interventions, resource distribution and ultimately health outcomes. It includes overviews of indigenous perspectives, the New Zealand and Australian health systems, collaboration plans and success indicators.

In ratifying the Convention on the Rights of Disabled Persons, the New Zealand Government has undertaken to include the voices of disabled people. For Government and others to partner in taking this Strategy on board in policy and decision-making is to respect the wishes of people living with cerebral palsy. In the spirit of inclusion and upholding the right to participation, it is more than the right thing to do, or the nice thing to do, it is the most effective thing to do. Where disabled people are organised and proactive in having a say in their own way and Governments are genuine in responding, this leads to better outcomes in policy, practice and the lives of disabled people.

Paula Tesoriero, New Zealand Disability Rights Commissioner

> “It’s important to understand that individuals with CP have unique needs and desires, we should not be lumped together or assumed to want the same thing just because we all have CP.”

Executive Summary

Aim and Objective of The Strategy

Our vision is a society where every person with cerebral palsy, and their family, have a positive quality of life and are supported and empowered to have control over their own life choices. Our vision is also to prevent cerebral palsy, minimise its impact, improve outcomes and promote change that fosters inclusion.

The mission of the Australian and New Zealand Cerebral Palsy Strategy is to improve the health, function, participation and quality of life of individuals with cerebral palsy and their families, through advocating for the provision of optimal healthcare and disability support, excellence in research and enhanced community knowledge. This will help achieve a more inclusive and accessible society.

Cerebral palsy is the most common physical disability in childhood and people with cerebral palsy experience significant barriers in everyday life. Complex and lifelong physical, medical, educational and social needs associated with cerebral palsy remain unmet. Furthermore, relative to the condition's prevalence, cerebral palsy remains under-recognised both at a societal level and within the political arena.

This lack of recognition has significant negative implications for people with cerebral palsy and their families. Some people with cerebral palsy are not being provided the supports and opportunities necessary to develop and thrive. Multiple and cumulative lost opportunities can limit an individual's ability to reach their full potential. The long-term, complex nature of cerebral palsy means that cumulative lost opportunities experienced across the life span can lead to reduced economic participation in adulthood, greater need for supports, reduced independence and poorer quality of life, all of which correlate with poorer individual, societal and economic outcomes.

As such, a targeted Australian and New Zealand Cerebral Palsy Strategy is necessary to:

- Document priorities identified by people with cerebral palsy, their families and professionals in the field of cerebral palsy, to establish targets for change;
- Inform key decision makers of unmet needs in the field of cerebral palsy;
- Optimise the efficient use of resources through building collaborative networks that act on identified priority areas;
- Increase viable and sustainable funding avenues through clear articulation of objectives determined by stakeholders; and
- Advocate for the needs of people with cerebral palsy and their families.

Achieving the priorities identified in The Strategy has considerable potential for benefit at an individual, societal and economic level.

Methodology

Comprehensive, independent community consultation was undertaken in order to create a document that

Image supplied courtesy of Cerebral Palsy Alliance

accurately represents the needs, opinions and priorities of people with cerebral palsy, their families and professionals working in the field. Consultation used a mixed methods approach including focus groups, webinar, an online survey about life satisfaction, an online questionnaire about specific content of a draft version of The Strategy, online open submissions where people could upload text, images or video, and telephone interviews.

139 people with cerebral palsy, family members, supporters and professionals working in the field completed the independent community consultation.

The Strategy was also presented at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference in Auckland 2018 where professionals provided feedback. Furthermore, an Expert Panel of 25 experts in the field (including people with cerebral palsy, family members and professionals) helped shape The Strategy.

Structure

Quality of life is an over-arching goal of The Strategy and is considered a necessary component of each goal outlined below as well as a benchmark with which to measure success. Quality of life for the purposes of The Strategy is “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [1].

The Strategy is comprised of four goal areas. Goals are structured to be person-centred and designed to encompass concepts of functioning, disability and contextual factors outlined by the International Classification of Functioning, Disability and Health (ICF) framework [2]. The goals of The Strategy are:

Inclusion and Engagement
To promote inclusion and active participation in all aspects of life, from an individual level to a community and societal level, for people with cerebral palsy and their families.

Health and Well-being
To improve health and well-being outcomes across the life span for people with cerebral palsy, to minimise impairment, maximise function and ensure life expectancy is in line with the broader population.

Intervention and Disability Support
To provide effective and timely evidence-based treatments and supports to ensure optimal outcomes for people with cerebral palsy and their families.

Prevention and Cures
To continue to reduce and ultimately prevent the future occurrence of cerebral palsy, and reduce the impact and severity of the damage to the brain for those born with and living with cerebral palsy, with the goal of finding cures. For the purpose of The Strategy we define ‘cures’ as highly effective treatment/s for cerebral palsy that convey significant improvements in function and/or reduction of symptoms.

Image supplied courtesy of St Giles, Tasmania

Under each goal are a range of short-term, medium-term and long-term priority objectives (outlined in the full strategy). Priority objectives are specific areas of unmet need and fall broadly within the sub-domains of support, advocacy, research, and knowledge translation.

The Strategy will undergo a five-yearly review to ensure accountability, measure progress, and allow for priority objectives to be updated in line with changing needs, so that it remains current and relevant.

Success Indicators

Success indicators are measurable and achievable outcomes for the current Strategy term. Success indicators will be used to benchmark progress towards achieving the priority objectives. In addition to goal-specific success indicators, The Strategy specifies a number of foundational success indicators which were identified as being necessary in order to achieve The Strategy mission and vision. Success indicators are not an exhaustive list, rather they aim to provide a guide for the implementation of priority objectives. A summary of success indicators is included below, with full details provided in the body of The Strategy.

Strategy Success Indicators

FOUNDATIONAL SUCCESS INDICATORS

1. Inclusion of cerebral palsy related variables in nationally collected data.
2. Better utilisation of National Disability Insurance Agency (NDIA), Individualised Funding (IF)/Enhanced Individualised Funding (EIF) and Disability Support System Transformation data to inform efficient use of funding for cerebral palsy.
3. Collection of common cerebral palsy related data elements across service providers and researchers funded by federal government agencies.
4. Continuity and long-term funding for State and National Cerebral Palsy Registers.
5. Inclusion of participation, quality of life and economic evaluation in all intervention and support research.
6. Increase in the proportion of allocated research funding in line with the rate of occurrence and functional impact of cerebral palsy relative to other conditions.
7. Inclusion of people with cerebral palsy, Aboriginal and Torres Strait Islander people and Māori peoples, and/or their families in co-designing all research and initiatives directly related to the field.

GOAL – INCLUSION AND ENGAGEMENT

1. Develop a suite of valid and reliable quality of life, engagement and participation measurement tools.
2. A measurable increase in the proportion of people with cerebral palsy achieving self-directed participation life goals.
3. A measurable increase in the number of adults with cerebral palsy that are gainfully employed above the minimum wage.
4. Inclusion of mobility and complex communication needs of people with cerebral palsy in built environment and transport accessibility legislation.
5. A 500% increase in the number of communication accessible spaces (hospitals, government buildings, local shops etc.) for people with cerebral palsy and their families, both in urban and rural areas.
6. Increase in community understanding of cerebral palsy and how to communicate with people with complex communication needs.
7. Increase in representation of people with cerebral palsy in print and screen media.

GOAL – HEALTH AND WELL-BEING

1. Increase in the number of Category 1 funded research projects examining, addressing and/or translating research targeting improved health and well-being outcomes for people with cerebral palsy, from antenatal to adulthood.
2. A measurable increase in the proportion of infants at risk, children, youth and people with cerebral palsy accessing preventative health screening/intervention.
3. Increase in funding and access to targeted active surveillance and treatment of health and well-being-related needs associated with cerebral palsy across the life span.
4. Inclusion of evidence-based content about cerebral palsy in nationally accredited training degrees and ongoing professional development programs.

GOAL – INTERVENTION AND DISABILITY SUPPORT

1. A significant reduction in the time gap between diagnosis of "at risk" of cerebral palsy and the provision of first intervention.
2. Establishment of a recognised working relationship between The Strategy Collaboration/Expert Panel and NDIA, IF/EIF and Disability Support System Transformation to inform, and advocate for, necessary interventions and disability supports for people with cerebral palsy.
3. A proportional increase in the number of interventions and disability supports available for people who do not currently have equitable access for example those people living outside major cities, socially and economically disadvantaged peoples, and people of culturally and linguistically diverse backgrounds.
4. Increase in the number of services, supports and interventions available to Aboriginal and Torres Strait Islander people and Māori peoples that reflect their cultural beliefs and practices.
5. Obtain data documenting the breakdown of national funding allocated for services, supports, and interventions both by severity level and across the life span to inform, help refine and advocate for necessary and optimal funding provisions for people with cerebral palsy.
6. A more streamlined approach to state and national education, so that people with cerebral palsy receive the same level of support for all national exams (NAPLAN and HSC, SATs, National Certificate Educational Achievement (NCEA) Part I, II and III) as has been provided throughout their schooling, without additional application processes.

GOAL – PREVENTION AND CURES

1. Greater levels of funding committed to understanding the causes of cerebral palsy and identifying new preventative, curative and ameliorating strategies aimed at reducing the impact of cerebral palsy.
2. Implementation of best practice strategies for preventing cerebral palsy in at least 80% of major public hospitals across Australia and New Zealand.
3. Earlier diagnosis of children with cerebral palsy before 12-months of age (from 52% to 70% diagnosed before 12-months).
4. Reduction in the severity of cerebral palsy (from 1 in 3 children unable to 1 in 4 children unable to walk).

CONCLUSION

The Australian and New Zealand Cerebral Palsy Strategy reflects a united voice informed by people with cerebral palsy, their families, professionals and researchers across Australia and New Zealand. Immediate action is necessary and warranted to address the priority areas identified within The Strategy. This will not only benefit people with cerebral palsy their families and supporters, but is expected to lead to improved economic and social outcomes for Australia and New Zealand.

Image supplied courtesy of Scope, Victoria

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Image supplied courtesy of Cerebral Palsy Alliance

1.0 Vision, Mission, Goals, Priority Objectives and Success Indicators

1.1 Vision

Our vision is a society where every person with cerebral palsy, and their family, have a positive quality of life and are supported and empowered to have control over their own life choices. Our vision is also to prevent cerebral palsy, minimise its impact, improve outcomes and promote change that fosters inclusion.

1.2 Mission

The mission of the Australian and New Zealand Cerebral Palsy Strategy is to improve the health, function, participation and quality of life of individuals with cerebral palsy and their families, through advocating for the provision of optimal healthcare and disability support, excellence in research and enhanced community knowledge. This will help achieve a more inclusive and accessible society.

1.3 Goals

Quality of life is an over-arching goal of The Strategy and is considered a necessary component of each goal outlined below as well as a benchmark with which to measure success. Quality of life for the purposes of The Strategy is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [1].

Goals are structured to be person-centred and designed to encompass concepts of functioning, disability and contextual factors outlined by the International Classification of Functioning, Disability and Health (ICF) framework [2]. Goal content is shaped by consumer reported priority areas for cerebral palsy.

The order of goals is not intended to be hierarchical in nature, but reflect equally important areas of need in the field of cerebral palsy.

The goals of The Strategy are:

Inclusion and Engagement
To promote inclusion and active participation in all aspects of life, from an individual level to a community and societal level, for people with cerebral palsy and their families.

Health and Well-being
To improve health and well-being outcomes across the life span for people with cerebral palsy, to minimise impairment, maximise function and ensure life expectancy is in line with the broader population.

Intervention and Disability Support
To provide effective and timely evidence-based treatments and supports to ensure optimal outcomes for people with cerebral palsy and their families.

Prevention and Cures
To continue to reduce and ultimately prevent the future occurrence of cerebral palsy and reduce the impact and severity of the damage to the brain for those born with and living with cerebral palsy, with the goal of finding cures.

1.4 Priority Objectives

Short-, medium- and long-term priority objectives are provided for each goal area. These were broadly conceptualised under four sub-domains.

Supports: Person-centred, high-quality, formal and informal supports are necessary to enable individuals to exercise their right to choice and control, and assist them to achieve their functional goals such as employment, education, communication, accommodation and self-care. Critical components of The Strategy are: (i) ensuring that appropriate formal supports (including intervention, services and supports) are available and are of high quality, and (ii) that informal support providers have access to the resources necessary to maintain their own well-being, the well-being of the person with cerebral palsy they support, and the well-being of other people they may support.

Advocacy: Community and policy advocacy are critical to address social injustices experienced by those with cerebral palsy, and to continue to make significant advances in all goal domains.

Research: Research is necessary to inform all goal domains and ensure continued development, progress and reform. Involving consumers in all aspects of research design, development and implementation, is critical to ensure appropriateness, relevance and impact of research outcomes.

Knowledge Translation: Translating the best available evidence and resources from research into practice, across all area of society, including for direct consumers, support networks, health professionals, key decision makers and the broader community, will lead to increased sense of empowerment and competency, and foster an understanding, accessible and accepting society.

1.5 Success Indicators

Success indicators are measurable outcomes achievable within the five-year term of The Strategy. Overall success indicators are provided for The Strategy as well as for individual goal areas. These were informed and shaped by community consultation. Achievement of success indicators is expected to directly translate to improvement in the priority objectives identified.

Image supplied courtesy of Cerebral Palsy Alliance

> “We have the same ambitions, goals and desires for happiness, independence, security and meaning in our lives as anyone else, regardless of the different path we may need to take to achieve it.”

“The importance of a national strategy should not be underestimated. At last, the priorities of the world of cerebral palsy will be determined by us, the very people who have to live in it and with it.”

1.6 Important Terminology

People with cerebral palsy – Anyone with a diagnosis of cerebral palsy, regardless of whether they are accessing supports or services.

Family – Any group of individuals that play an important role in an individual's life. May refer to immediate family, extended family or community members. Indigenous peoples, in particular, may have different definitions for the term.

Support Network – All informal and formal supports for an individual with cerebral palsy, including but not limited to family, friends, colleagues, health professionals, therapists, and any other individuals involved in the care, assistance or service provision for an individual with cerebral palsy.

Community – The broader network, geographical area and social structure in which an individual with cerebral palsy lives.

Indigenous peoples – Aboriginal and Torres Strait Islander people and Māori peoples, the original inhabitants or tangata whenua of Australia and New Zealand Aoteroa, respectively.

Culture – The ideas, customs and social behaviours of a particular group. May refer to Indigenous, migrant, disability or cerebral palsy culture within Australia and New Zealand.

Employment – A contractual arrangement where an individual agrees to complete tasks in return for payment. Types of employment include full-time, part-time, contractor, casual, temporary, seasonal and self-employment.

Volunteer – An agreement between an individual and another individual or organisation to complete tasks on an ongoing basis without payment.

Quality of Life – "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [1].

Intervention – Any treatment, support or service provided to help ameliorate impacts of cerebral palsy or maintain function.

Health – Mental and physical well-being. An absence of illness, injury or ailment. Note: while we adhere to and support the WHO's holistic definition of 'health', for the purposes of The Strategy and differentiating priority areas, when we refer to 'health' we refer to the traditional definition of 'health' above.

Disability Support – Any equipment or service (formal and informal) that helps a person to overcome barriers associated with having a disability.

Image supplied courtesy of Shannon Clough

Image supplied courtesy of Cerebral Palsy Alliance

Image supplied courtesy of Cerebral Palsy Alliance

2.0 Why Develop an Australian and New Zealand Cerebral Palsy Strategy?

Significant advances have been made in improving the quality of life of people with cerebral palsy, particularly over the last 10-15 years. These include the expansion of evidence-based services, enhanced individual participation with greater access to supports and technology, a strong research agenda leading to exponential knowledge growth and clinical advances, and greater recognition of cerebral palsy through initiatives such as World CP Day and the International Multidisciplinary Prevention and Cure Team - IMPACT for CP.

However, cerebral palsy remains the most common physical disability in childhood and people with cerebral palsy continue to experience significant barriers in everyday life. Complex lifelong physical, medical, educational and social needs uniquely associated with cerebral palsy, as opposed to disability in general, remain unmet. Furthermore, relative to the condition's prevalence, cerebral palsy remains under-recognised both at a societal level and within the political arena.

This lack of recognition has significant negative implications for people living with cerebral palsy and their families. People with cerebral palsy do not always receive the supports and opportunities necessary to develop and thrive. Multiple and cumulating lost opportunities limit an individual's ability to reach their full potential. This in turn has societal and economic implications, particularly for schemes such as the National Disability Insurance Scheme (NDIS). The long-term, complex nature of cerebral palsy means that lost opportunities experienced across the life span can lead to reduced economic participation in adulthood, greater need for supports, increased family involvement and costs, reduced independence and poorer quality of life, all of which correlate with poorer individual, societal and economic outcomes.

A targeted Australian and New Zealand Cerebral Palsy Strategy is therefore necessary to:

- Document priorities identified by people with cerebral palsy, their families and professionals in the field of cerebral palsy, to establish targets for change;
- Inform key decision makers of unmet needs in the field of cerebral palsy;
- Optimise the efficient use of resources through building collaborative networks that act on identified priority areas;
- Increase viable and sustainable funding avenues through clear articulation of objectives determined by stakeholders; and
- Advocate for the needs of people with cerebral palsy and their families.

Achieving the priorities identified within The Strategy will undoubtedly lead to benefits at an individual, societal and economic level.


BOCCIA

> “As a community of people living with CP or supporting those living with CP… we need … to band together and lobby for more services, opportunities and community understanding.”

3.0 Review Period

The Strategy is comprised of current short-term, medium-term and long-term priority objectives for the field of cerebral palsy in Australia and New Zealand. Success indicators are measurable outcomes, achievable within The Strategy term, which will be used to benchmark progress made towards meeting priority objectives.

The Strategy will undergo review five years following its release. This will ensure accountability, enable tracking of progress made towards meeting the priority objectives, and allow for priority objectives to be informed and updated by people with cerebral palsy and their families in line with changing needs, so that The Strategy remains current and relevant.

Image supplied courtesy of Cerebral Palsy Alliance

Image supplied courtesy of Cerebral Palsy Alliance

4.0 Background to Cerebral Palsy

4.1 Definition and Impact

'Cerebral palsy' describes a cluster of permanent physical disabilities affecting an individual's movement and/or posture. It is caused by non-progressive damage to the developing brain, typically during the antenatal or perinatal period. Although the primary neuropathology of cerebral palsy is non-progressive in nature, the clinical presentation can change across the life span, impacting aspects of body movement, muscle control/coordination, and posture and balance. People with cerebral palsy are also more likely to experience associated difficulties at significantly higher rates than the general population. These difficulties can include chronic pain, epilepsy, intellectual impairment, vision impairment, hearing impairment, sleep disorders, behavioural difficulties, difficulties with eating and drinking, and communication difficulties [3].

4.2 Aetiology and Diagnosis

Multiple risk factors are associated with increased risk of cerebral palsy antenatally, perinatally and postnatally; however, the direct causal pathways leading to the brain injury are often unknown. The Australian Cerebral Palsy Register Report (2018) identified that, when compared to the general population, infants with cerebral palsy are more likely to be male, born preterm, from a multiple birth and have low birth weight for gestational age [4]. Specifically, 43% of infants with cerebral palsy were either born prematurely (less than 37 weeks' gestation) or had low birth weight for gestational age (less than 2,500 grams), compared to 8.7% and 6.5% of the general Australian population, respectively [5].

Until recently, cerebral palsy was typically diagnosed when the infant was aged between 12 and 24 months, once it was easily identifiable that an infant had a motor impairment. Now, due to advances in knowledge gained from high quality research, guidelines for accurate diagnosis are available for children aged from 0 to 5 months, and also for those older than 5 months [6]. Children can be accurately diagnosed with cerebral palsy or "at high risk of cerebral palsy" up to and including 5 months of age (corrected for prematurity) using a combination of the following methods:

- History taking to identify risk factors;
- A neurological examination using a standardised measure such as the Hammersmith Infant Neurological Evaluation [7], as cut-off scores for cerebral palsy are available;
- A standardised assessment of motor and movement quality, for example using Prechtl's General Movements Assessment [8] for infants;
- Magnetic Resonance Imaging (MRI) of children with suspected brain injury.

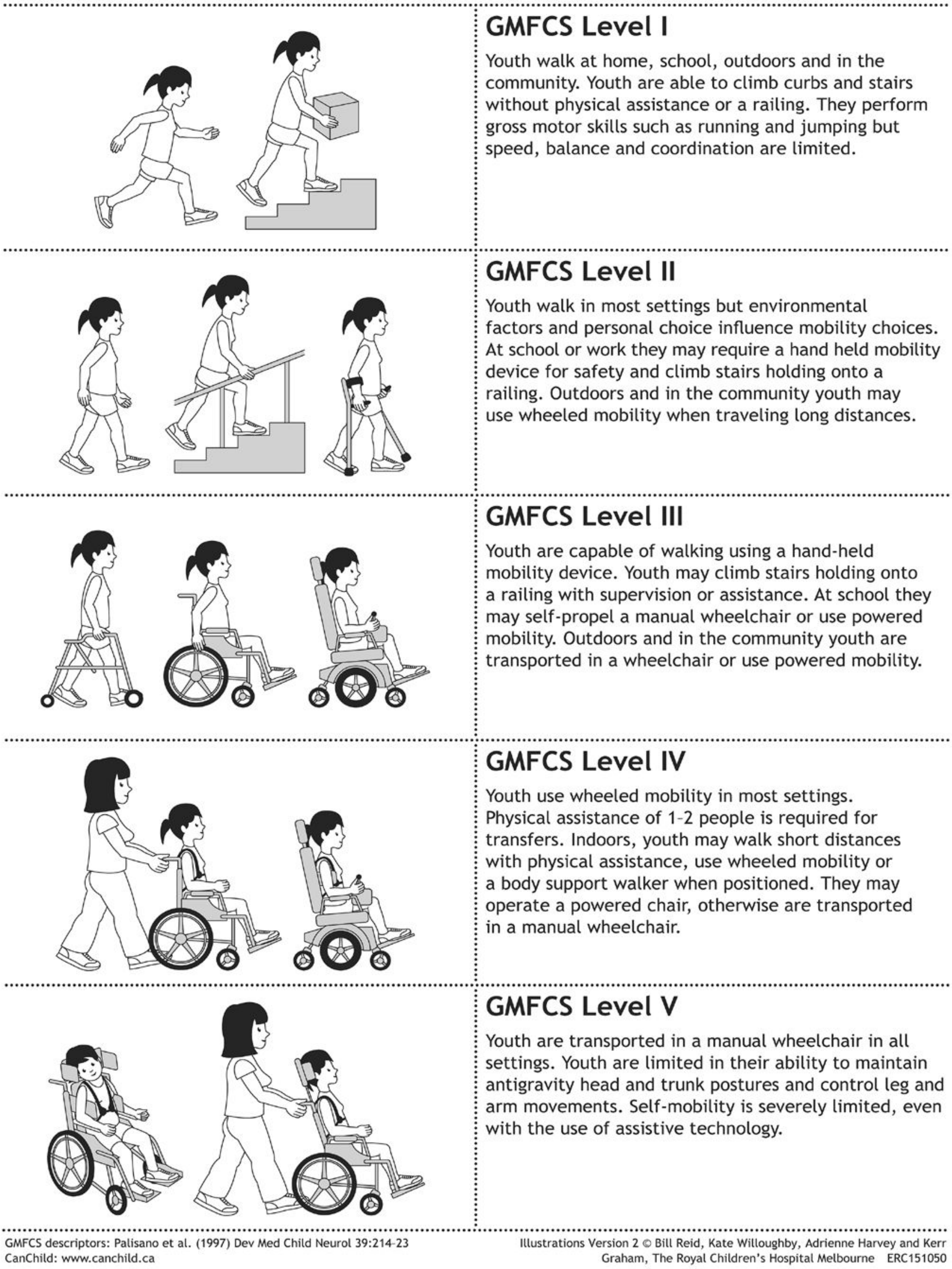
The significant lowering of the age of diagnosis has opened up a window for potential early intervention aimed at reducing the severity and/or impairments associated with cerebral palsy.

4.3 Presentation and Classification

The presentation of cerebral palsy is unique to each individual and varies by type and severity. The Gross Motor Classification of Function System - Expanded and Revised (GMFCS-E&R) [9] is a system used to understand the severity of functional mobility and posture. This system has severity levels from level I (minimal functional motor impairment) to level V (significant functional motor impairment) and assesses the individual's movements including sitting and walking, with and without mobility aids, to provide clinicians and families with a clear description of the person's functional motor abilities.

> **"I would like people to stop talking about me in front of me. People seem to think that because I can't speak that I can't hear. That's not true."**

GMFCS E & R between 12th and 18th birthday: Discriptors and illustrations



GMFCS Level I

Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.

GMFCS Level II

Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.

GMFCS Level III

Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.

GMFCS Level IV

Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.

GMFCS Level V

Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham, The Royal Children's Hospital Melbourne ERC151050

Figure reproduced from: Gross Motor Function Classification System - Expanded & Revised (2019). Original reference: [10] Available at: https://canchild.ca/system/tenon/assets/attachments/000/002/114/original/GMFCS_English_Illustrations_V2.pdf

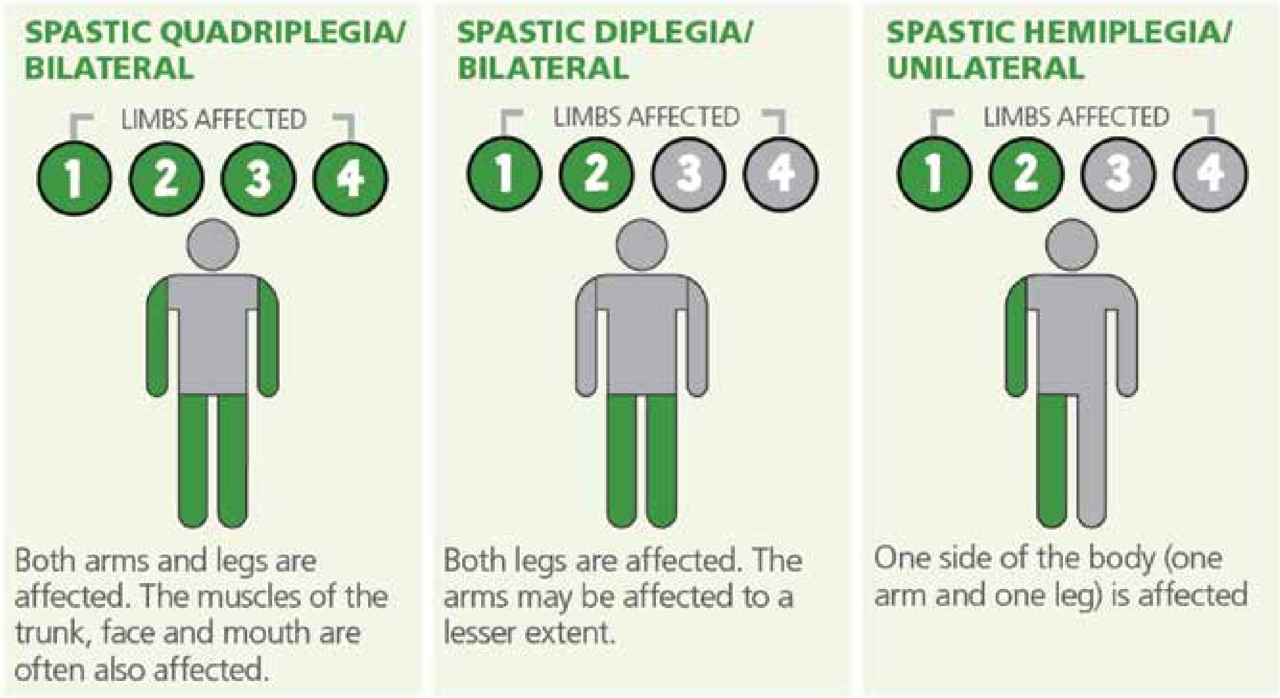


Figure abstracted from: World CP Day, What is cerebral palsy? (2017).
https://worldcpday.org/tools/#1493959825296-f73f835a-071e

A person's fine motor dexterity is also often impacted by cerebral palsy. The Manual Ability Classification System (MACS) [11], with levels ranging from I to V, is used to describe how well a child can manipulate objects with their hands. Cerebral palsy can also be classified according to both the degree of impact on various limbs and the predominant distribution and motor type of muscle or movement impairment. Unilateral cerebral palsy, also known as hemiplegia, occurs when one side of the body is impacted, whereas bilateral cerebral palsy is where both sides of the body are impacted (diplegia for both lower limbs and quadriplegia for four limb involvement). Types of muscle or movement impairments include spasticity (occurring in 85% of all cerebral palsy cases); dyskinesia (occurring in 7% of all cerebral palsy cases); and ataxia (occurring in 4% of all cerebral palsy cases) [4]. Many people with cerebral palsy will have a mixed motor type, for example, both spasticity and dyskinesia.

The presentation of associated impairments also varies greatly across individuals. Speech and communication is one area that particularly impacts an individual's ability to actively and meaningfully participate in the community. People with cerebral palsy are more likely to have dysarthria, making it difficult to understand speech at times, and one in four people with cerebral palsy are unable to speak. Speech can be classified using the Vikings Speech Scale, 2010© [12] with severity levels ranging from I (speech not affected by motor disorder) to IV (no understandable speech). However, with advances in assistive technologies, gaining an understanding of how effectively a person can communicate via any means available to them (speech or communication aid) is also important and can be assessed using the Communication Function Classification System [13] with levels ranging from I to V.

4.4 Economic Impact

Cerebral palsy is the most common physical disability in childhood. Internationally, 17 million people are estimated to have cerebral palsy. In Australia, 1 in 700 children are diagnosed with cerebral palsy [4], and approximately 35,522 people were estimated to have cerebral palsy in Australia in 2018 [14]. This number is expected to increase to 46,790 by 2060 [14]. The cost associated with caring for people with cerebral palsy in Australia in 2018 was estimated at $85,184 per person with cerebral palsy per year, with an estimated total expenditure of cerebral palsy in Australia of $3.03 billion per year [14]. When including the value of lost well-being, this increased to over $145,000 per person per year, with a national annual cost of $5.17 billion in 2018 [14]. These costs are expected to be similar for people with cerebral palsy in New Zealand.

Individuals with cerebral palsy and their families bear 47% of the total financial costs of caring for someone with cerebral palsy [14]. State and Federal Government bears around 36% (with Federal being the major contributor mainly through taxation revenues forgone and welfare payments), employers 6% and the rest of society approximately 11% [14].

Image supplied courtesy of Cerebral Palsy Alliance

Total costs of cerebral palsy in Australia in 2018, by bearer (% of total)

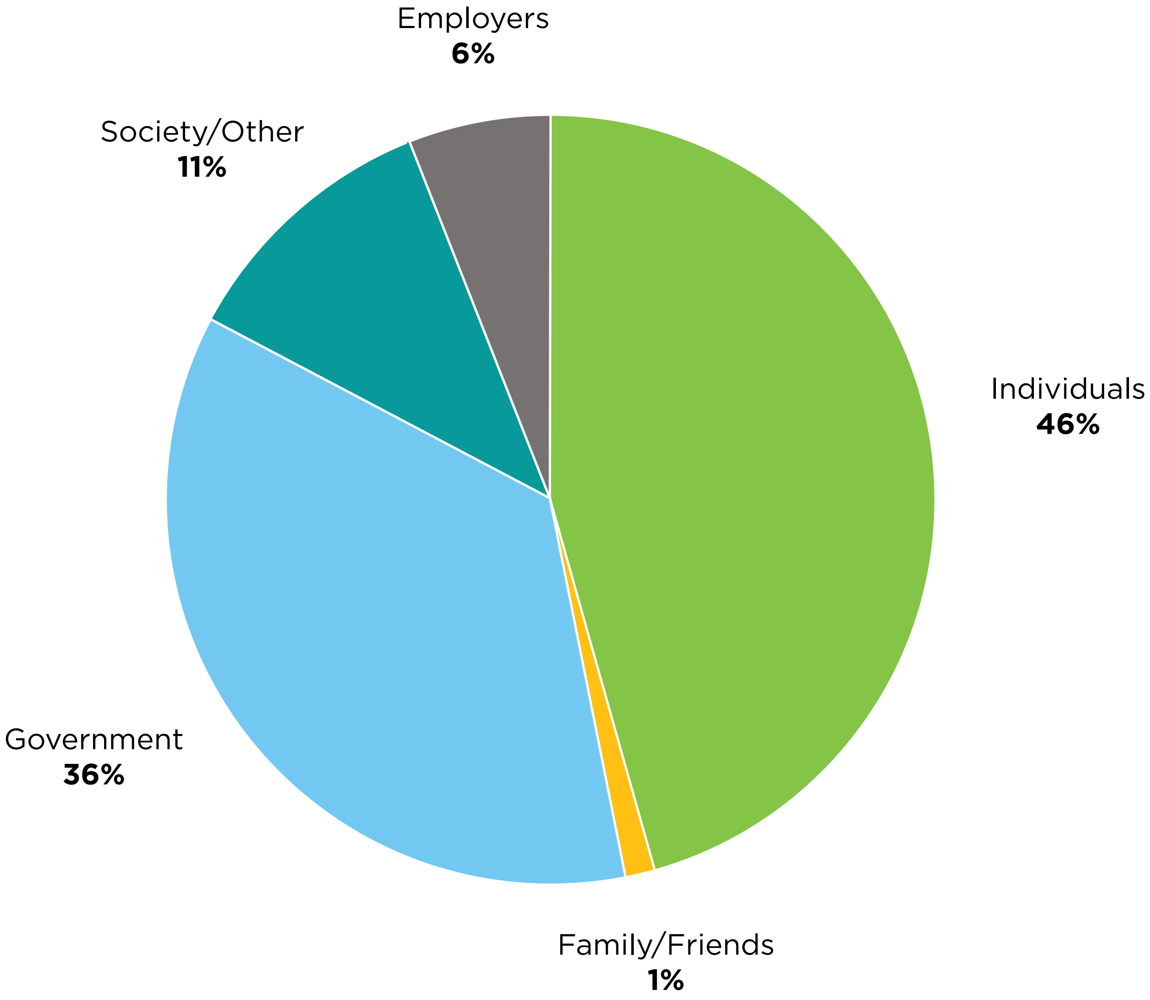


Figure adapted from: Deloitte Access Economics (2019) The cost of cerebral palsy in Australia in 2018. Report prepared for Cerebral Palsy Australia, Cerebral Palsy Alliance and The Australasian Academy of Cerebral Palsy and Developmental Medicine [14].

4.5 Service and Support Needs across the Life span

Due to the complex nature of cerebral palsy and associated impairments, service, support and intervention needs vary widely between individuals. People with cerebral palsy and their families also require different services, supports and intervention across the life span. The following categories reflect some common types of services, supports and interventions that people with cerebral palsy and their families need across the life span.

4.5.1 Early detection and intervention

Early detection and early intervention are the first pivotal steps necessary to ensure a child with cerebral palsy is provided the best opportunity to reach their full potential. Early intervention from the time of birth and through the first five years of life is critical. During early childhood the developing brain undergoes critical periods of development. Evidence demonstrates that providing children with appropriate environmental stimulation and intervention at an individualised 'just-right' level is essential to optimise neuroplasticity and achieve potential improvements during these critical periods [15, 16].

4.5.2 Preventative health screening

Research shows that preventative health screening for common difficulties associated with cerebral palsy is critical for long term health outcomes; a Swedish surveillance program for people with cerebral palsy, CPUP, has demonstrated the ability to prevent hip dislocation and minimise contractures and scoliosis through active screening processes [17-19]. Significantly reducing the need for later intervention, such as orthopaedic surgery.

Moreover, general preventative health screening such as breast screening, cervical screening test, vaccinations, prostate examinations and skin checks are equally important for people with cerebral palsy, however are often not accessible.

4.5.3 Education

Research demonstrates that children with cerebral palsy are significantly less likely to participate in national standardised testing than their typically developing peers; only 47% of children with cerebral palsy with educational data available participated in national testing [20]. One of the reasons cited for lack of participation was functional disability. Access to education is a basic human right. Greater acceptance and inclusion of accommodations and disability supports, to remove classroom barriers and allow children with cerebral palsy to participate in education and demonstrate their abilities, is necessary in order to ensure children are supported in their education to reach their full potential.

4.5.4 Assistive technology

The WHO defines assistive technology as an umbrella term for any device or system that enables a person to perform a task that would otherwise be too hard to execute or that facilitates how a task can be performed [21]. The most common types of assistive technologies used by people with cerebral palsy are mobility aids and assistive communication technology. However, with constant advancement of technology, the types and potential for assistive technology to support people with cerebral palsy are ever-growing. Mobility aid needs change frequently across childhood as the child grows and has different requirements. People with cerebral palsy can require multiple mobility aids to allow access in different environments, for example: a walking frame for around the house and short distances, and a wheelchair for longer distances. Ensuring these needs are properly met and provisions are available for changing needs is essential to ensure that each person with cerebral palsy can access and participate fully in their environment.

Assistive communication technology allows people with cerebral palsy and complex communication needs to communicate effectively. Assistive technology for communication includes low-tech devices such as picture boards, and high-tech devices such as switches to control computers and eye-gaze technology. Again, device appropriateness is unique to each individual and people may require different devices for different situations, for example eye-gaze in the classroom and a picture board when at home.

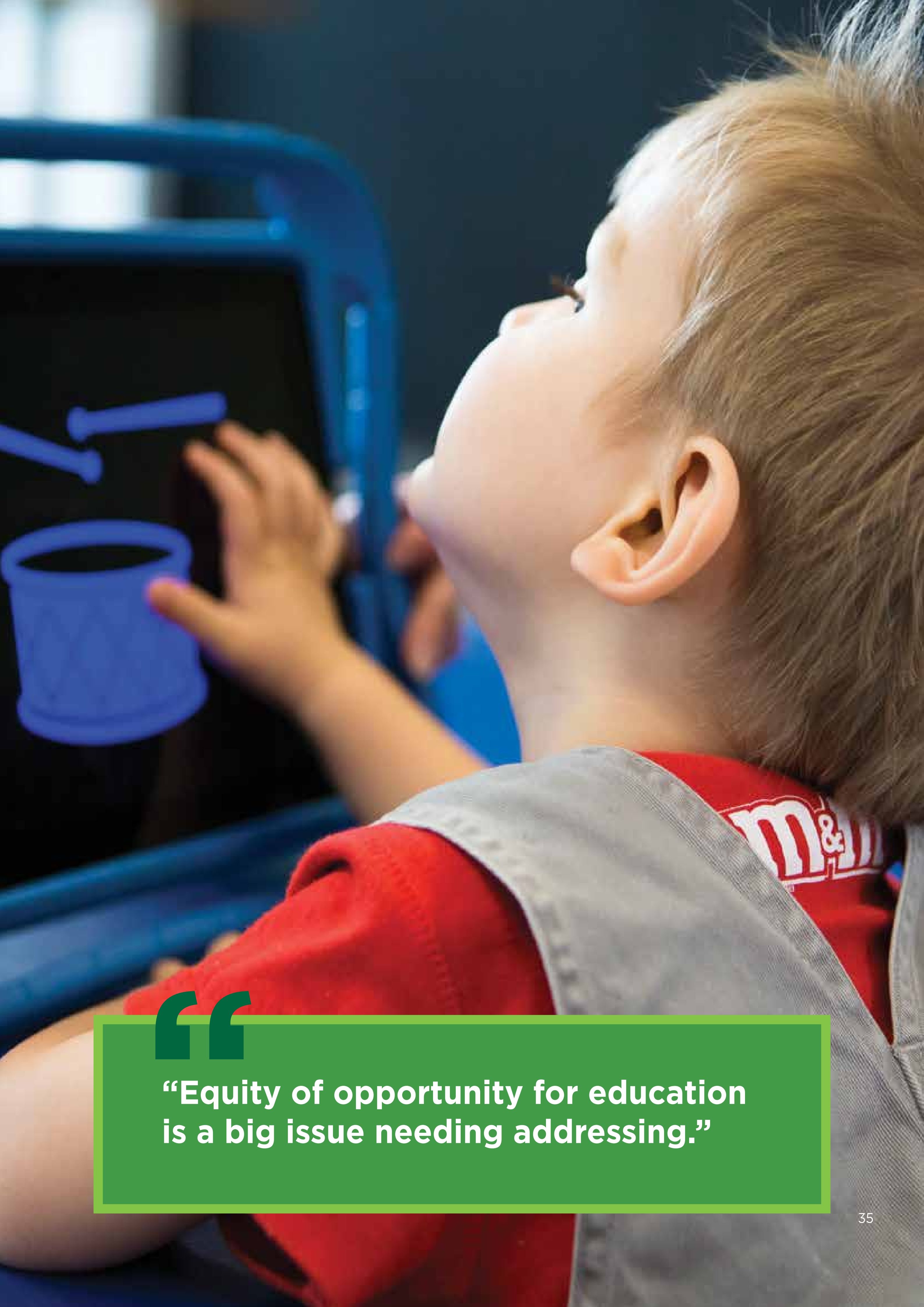
4.5.5 Employment, volunteering, accommodation and meaningful relationships

Supports and services in adulthood are essential to assist adults with cerebral palsy to achieve their goals. Research demonstrates that people with cerebral palsy are less likely than their typically developing peers to achieve life goals such as employment, independent living and meaningful relationships [22]. Often this is due to societal barriers and lack of opportunities. Achievement of these goal areas in adulthood is however associated with greater well-being and participation. As such, supporting people with cerebral palsy and the community to remove barriers and create more inclusive environments, is essential. Furthermore, provision of appropriate supported accommodation alternatives is necessary to meet varying levels of need.

4.5.6 Ageing in place

As the life expectancy for people living with cerebral palsy improves, there should be adequate services and support in place to enable people with cerebral palsy to 'age in place'. Aging in place is a term used to describe a person living in the residence of their choice, for as long as they are able, as they age. People with cerebral palsy have the right to supported ageing in place, and may require additional services and supports, to maintain their quality of life and give control over their independence and dignity as their needs change with age.

Image supplied courtesy of Cerebral Palsy Alliance



“Equity of opportunity for education is a big issue needing addressing.”

Image supplied courtesy of Cerebral Palsy Alliance

5.0 International Conventions and Legislation

The Strategy identifies important domains for improvement for the cerebral palsy field in Australia and New Zealand. The Strategy is informed and underpinned by international and national conventions which support the rights of people with cerebral palsy. These conventions are briefly outlined below so that it is clear how The Strategy embodies and advances existing conventions and legislation.

5.1 Convention on the Rights of Persons with Disability

The United Nations Convention on the Rights of Persons with Disability (CRPD) [23] was established in December 2006 and ratified in Australia and New Zealand in 2008. The purpose of the convention "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". This is achieved through the convention detailing the rights of individuals with disability and providing a framework through which countries can protect the rights of individuals with disability and dispel practices that constitute discrimination. The primary principles of the convention focus on: respect for individual dignity; autonomy; independence and decision making; removing discrimination; participation and social inclusion; respect and acceptance of diversity; equal opportunity (including that between males and females); accessibility; and respect for the evolving ability of children with disability.

5.2 Australian Legislation and Implementation of the Rights of Persons with Disability

The primary principles of the CRPD are legislated in Australia via the Disability Discrimination Act 1992, the most recent amendment of which occurred in April 2018 [24]. This Act stipulates that in Australia it is against the law to discriminate on the basis of disability in the areas of employment, education, accommodation, sport, access to premises, provision of goods, services or facilities, purchasing of land, activities of clubs and associations, and in the administration of Commonwealth Government laws and programs (e.g. voting facilities).

Despite ratification of the convention and enactment of legislation against discrimination on the basis of disability in Australia, a report by the National People with Disabilities and Carer Council in 2009, 'Shut Out: The Experience of People with Disabilities and their Families in Australia' [25] highlighted ongoing concerns for people with disability in Australia, particularly with regard to employment, supports and services, access, education, social inclusion and community participation. As such, the National Disability Strategy 2010-2020 [26] was developed to help advocate for disability-related issues in the public policy arena, to guide government in both mainstream and disability-specific areas of policy making, to improve access to services for people with disability, and to promote inclusion of people with disability. The National Disability Strategy encompasses the following key policy areas: inclusive and accessible communities; rights protection, justice and legislation; economic security; personal and community support; learning and skills; and health and well-being.

In addition to incidents of discrimination, inquiries and reports have shown that people with disability are more likely to experience violence, abuse, neglect and exploitation than people without disability. In response, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in Australia was established by the Governor-General of the Commonwealth of Australia on the 4th April 2019 [27]. The purpose of the Royal Commission is to help to inform Australian governments, institutions and the wider community on how to prevent, and better protect, people with disability from experiencing violence, abuse, neglect and exploitation in the future. A final report is expected in April 2022.

Aboriginal and Torres Strait Islander people are the original inhabitants of Australia and the custodians of the land. However, Australia does not have specific legislation concerning Indigenous Australians with disability. Rather, the National Agreements in other key areas of Commonwealth-State policy collaboration aim to improve services for all Australians, including Indigenous Australians. Accordingly, the National Indigenous Reform Agreement (NIRA) [28], which was established to frame the task of "Closing the Gap" in Indigenous disadvantage, references the National Disability Agreement [29] as the Council of Australian Governments (COAG) national policy framework responsible for improving Indigenous-specific outcomes under the "building block" of Health. The National Disability Agreement being a high-level agreement between the Australian and state and territory governments for the provision of disability services for people with disability.

Despite these national agreements, Aboriginal and Torres Strait Islander people continue to experience higher rates of disability than non-Indigenous Australians. In 2012-2013, Indigenous Australians were twice as likely as non-Indigenous Australians to have severe or profound disability (based on age-standardised rates) [30]. From the 2009 'Shut Out' report [25], consultation revealed that people with disabilities from an Aboriginal or Torres Strait Islander background feel they face a 'double disadvantage', and additional attention must be given to the particular experiences and needs of Aboriginal and Torres Strait Islander people with disabilities. In response, the

National Disability Strategy highlights consideration of strategies to address the needs of Aboriginal and Torres Strait Islander people with disability as an area for future action [26].

The ICF, established by the WHO and endorsed by all Member States in 2001, provides a uniform framework for conceptualising 'health' and 'disability' internationally. The ICF focuses on functioning and impact, which goes beyond traditional medical models of specific diagnoses, and instead looks at how a range of abilities, impairments and limitations interact with environmental, contextual and personal factors, and all contribute to an individual's functioning.

In line with the ICF focus on function and person-centredness, and to further protect the rights of persons with disability, the funding model for disability in Australia has recently undergone significant reform with the enactment of the NDIS Act 2013 [31] and subsequent establishment of the National Disability Insurance Agency (NDIA), with full scheme implementation commencing on the 1st of July 2016 (following a pilot period). This Act established a new way of providing individualised funding support for people aged 0-65 with a disability, their families and their carers. Funding packages are provided based on the level of reasonable and necessary support an individual requires to lead an average life, which includes achieving goals such as independence, community involvement, employment and overall well-being. Unlike previous disability funding models, the NDIS enables the individual with disability to exercise choice and autonomy over their own support and goal achievement and aims to provide a consistent approach to disability service provision nationally. The Act also acknowledges the important potential of early intervention in moderating future disability and is thus provided for under the Act.

Despite a number of actions undertaken to implement the key principles of the CRPD, a review by the United Nations Committee on the Rights of Persons with Disabilities at its 10th session (September 2013) [32] raised a number of significant ongoing concerns around the treatment of people with disability in Australia. Areas of particular concern raised included low rates of employment, over representation of people with disability in the criminal justice system, vulnerability of Aboriginal and Torres Strait Islander people with disability, high rates of violence, abuse and exploitation of women with disability, the existence of institutionalised accommodation services, a lack of uniform legislation prohibiting sterilisation and other medical intervention without informed consent for people with a disability, a lack of knowledge around effectiveness of education policies for children with disability, and general concerns around the lack of choice for people with disability.

National initiatives such as the COAG Disability Reform Council have acknowledged the rapidly changing disability landscape in Australia and have identified the need for comprehensive national strategies to guide disability framework in Australia. As such, at its first meeting on 30 April 2018 the COAG Disability Reform Council agreed to immediately begin developing a national disability framework and a supporting action plan for beyond 2020 which will respond to the altered landscape associated with full implementation of the NDIS and related changes in community attitudes towards disability [33]. The Australian and New Zealand Cerebral Palsy Strategy, through providing a united voice of key priorities for the field of cerebral palsy, is critical to informing such initiatives and continuing to improve the landscape of disability in Australia.

5.3 New Zealand Legislation and Implementation of the Rights of Persons with Disability

The primary principles of the CRPD are legislated in New Zealand through a number of avenues: the New Zealand Bill of Rights Act 1990 [34], the Human Rights Act 1993 [35], specialised legislation e.g. the Education Act 1989 [36] and the New Zealand Public Health and Disability Act 2000 [37], and through changes made to 23 statutes upon ratification of the Convention.

The first New Zealand Minister of Disability Affairs was appointed in 1999, specifically to oversee the government's support of individuals with disabilities in society such as advocating for specific programmes and ensuring the entitlements already in place are accessible to as many people as possible. In 2008, New Zealand became a signatory to the United Nations CRPD. Consequently, New Zealand is required to report on progress in ratifying the key tenants of the CRPD.

In 2001, New Zealand launched The New Zealand Disability Strategy [38] which is a government framework that aims to remove barriers for people with disabilities to participate fully in society. Key objectives include fostering leadership amongst youth with disabilities, promotion of and respect for people with disability amongst the general public, provision of access to education and opportunities for employment, and collection of relevant and specialized information about disability to enable effective advocacy. The government is responsible for regularly reporting on its progress in implementing the original strategy objectives and subsequent policy amendments. The New Zealand Disability Strategy has since been revised and updated in recognition of the continued poorer outcomes for people with a disability in New Zealand, with a 2016 to 2026 version currently in place [39]. The New Zealand Disability Strategy 2016-2026 has eight core outcomes areas against which progress is tracked: education, employment and economic security, health and well-being, rights protection and justice, accessibility, attitudes, choice and control, and leadership.

The New Zealand government is now looking to change traditional funding avenues for people with a disability, which were primarily accessed through relevant public health, disability and education ministries, the Accident Compensation Corporation when disability is the result of an injury, or through private funding avenues. In 2009, the government introduced Individualised Funding (IF), which states that the person with disabilities should be able to select their caregivers by having control of their funding package. Here, people with a disability who are able to manage their own funding can receive

image supplied courtesy of Shirls Wong

funding packages to cover the costs of personal care supports and respite. However, this funding does not cover costs associated with things such as equipment, necessary home adaptations or recreation. Moreover, in October 2018, MidCentral New Zealand began piloting a Disability Support System Transformation. Based on the 2011 'Enabling Good Lives' movement, this transformation aims to ensure people with a disability and their families have choice and control over their lives.

5.4 Te Tiriti o Waitangi / The Treaty of Waitangi

All New Zealand policy development and public strategic decision making is guided by the Treaty of Waitangi / Te Tiriti o Waitangi (the Treaty) [40]. Signed in 1840 and updated as the Treaty of Waitangi Act 1975 [41], the Treaty originally enabled immigrant and Māori people to live together under a set of common agreements and laws, and continues to protect the rights of Māori people in New Zealand. The Treaty recognises Māori as tangata whenua and signifies their important relationship with the Crown and New Zealand in general. The Treaty of Waitangi is a founding human rights document and bestows specific rights and protects all New Zealanders. Most Māori people with a disability identify as Māori first. The importance of their cultural identity, which encompasses language, whānau, cultural principles, practices and linkages to the land through genealogy, is paramount to how they live their day to day lives in both Te Ao Māori and Te Ao Pākehā.

The primary principles of the Treaty – partnership, participation and protection – continue to form the foundation for the relationship between Māori people and the government. Partnership involves working together with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services. Participation requires Māori to be involved at all levels of the health and disability sector, including in decision-making, planning, development and delivery of health and disability services. Protection involves the government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.

These core principles guide health and disability decision making in New Zealand, ensuring the rights of Māori and non-Māori people are reflected in all decisions. One area in which the positive impact of the Treaty of Waitangi can be seen is through the inclusion of Māori concepts of health and well-being in legislation, strategies and services. 'Hauora' outlines concepts of well-being, encompassing 'Taha tinana' – Physical well-being, 'Taha hinengaro' – Mental and emotional well-being, 'Taha whānau' – Social well-being and 'Taha wairua' – Spiritual well-being. This conceptualisation of well-being, recognised by the WHO, highlights the interconnectedness of these four dimensions in shaping overall well-being.

Image supplied courtesy of The Cerebral Palsy Society of New Zealand

Image supplied courtesy of Cerebral Palsy Alliance

> **“Sometimes I felt that I was discriminated against when looking for appropriate roles matching my skillset.”**

5.5 Convention on the Rights of the Child

In addition to rights surrounding disability, rights of children with cerebral palsy are also protected under the United Nations Convention on the Rights of the Child (CRC) [42]. The CRC was established in 1989 and ratified in Australia in December 1990 and in New Zealand in 1993. The CRC aims to protect and promote a child’s right to not just survive free from hunger, want, abuse and neglect, but their right to thrive, learn, grow, reach their full potential, and to have their voices heard. The CRC is founded on the guiding principles of non-discrimination, the best interests of the child, the right to life, survival and development, and the right to participate. These are considered underpinning requirements necessary to realise the rights covered by the CRC. Within this context, rights can be summarised under three categories: rights to survive and develop, rights to protection and rights to participate. It outlines that children are not the property of a parent nor objects of care, but rather highlights children as individual human beings with their own rights and responsibilities appropriate to their age and development, existing as members of a family and a community. It expressly recognises parents’ paramount role in the raising of children, and the importance of adapting parenting and disciplining styles to address issues of rights relative to age and development. Specific environmental factors, resources, skills and contributions necessary to achieve the rights for all children internationally are incorporated.

5.6 Australian Legislation and Implementation of the Rights of the Child

Although the CRC was ratified in Australia in 1990, Australia is yet to develop a national act expressly protecting the rights of the child. All states have implemented measures protecting the rights of children and some rights are innately protected under other national legislation such as the Disability Discrimination Act 1992, Family Law Act 1975 [43], the Education and Care Services National Law Act 2010 [44], with state based provisions, and the Australian Education Act 2013 [45]. Furthermore, in 2009 a “National Framework for Protecting Australian Children 2009-2020” [46] was developed along with a “National Early Childhood Development Strategy” [47]. In 2010, the “National Plan to Reduce Violence Against Women and their Children 2010-2022” [48] was developed, and in 2015 the “Disability Standards for Education 2005” [49] were reviewed which further support specific rights of children. Nevertheless, a lack of national legislation specifically pertaining to the rights of the child has resulted in fragmentation of state-based systems, and inconsistencies with regards to the degree to which rights are enforced and upheld.

5.7 New Zealand Legislation and Implementation of the Rights of the Child

Ratified in New Zealand in 1993, the rights of children in New Zealand are protected through the Office of the Children’s Commissioner. This is an independent Crown entity responsible for implementing the articles set out in the CRC. Originally established as a Children’s Commissioner in 1989 under the Children, Young Persons, and Their Families Act 1989 [50], the Office of the Children’s Commissioner was further strengthened under the Children’s Commissioner Act 2003 [51]. Through this Office, the Children’s Convention Monitoring Group was established, and is responsible for providing regulatory reporting on the New Zealand government’s implementation of the CRC.

The rights of vulnerable children are also protected under the Vulnerable Children’s Act 2014 [52], designed to protect and improve the well-being of vulnerable children, following recommendations from the White Paper for Vulnerable Children released in October 2012 [53]. The White Paper then prompted development of the Children’s Action Plan [54]; a cross-sector programme aimed at protecting vulnerable children, reducing child abuse and neglect and creating local multidisciplinary ‘children’s teams’ throughout New Zealand.

Image supplied courtesy of Cerebral Palsy Alliance

6.0 A Case for Change

> **“[Family and carers] have a huge impact on the ability for a meaningful life.”**

Multiple government initiatives aimed at reducing barriers and increasing participation for people with disability are being or have been successfully implemented in New Zealand and Australia e.g. the National Disability Agreement [29], The National Disability Strategy, the NDIS, IF/EIF, and Disability (Access to Premises – Buildings) Standards 2010 [55]. Such initiatives have the potential to positively impact people with disability, their families and society.

While people with cerebral palsy do stand to benefit from these initiatives, the unique and complex challenges faced by people with cerebral palsy, when compared to other physical disabilities, means that, in the current climate, people with cerebral palsy are likely to continue to experience significant barriers. Furthermore, the high degree of individual variability in cerebral palsy presentation adds to societal misconceptions about cerebral palsy, potentially impacting the value received from these initiatives.

As cerebral palsy is the most common physical disability in childhood, with continued impacts across the life span, we stand to gain significantly as a society by remaining informed about the needs of people with cerebral palsy and developing policy and implementing actions to meet the needs of people with cerebral palsy and their families.

The Strategy provides a framework outlining goals and priority objectives for cerebral palsy, informed by people with cerebral palsy, families and professionals working in the field. This framework will highlight areas of unmet need, provide a united voice to inform decision makers, enable a targeted approach to increase efficiency of expenditure and assist with advocacy.

With the current roll-out of the NDIS in Australia, and the trials of EIF and Disability Support System Transformation in New Zealand, the timing is critical. This framework will support ongoing, targeted development and implementation of the best available evidence-based treatments, services and supports. In addition, addressing the priority areas outlined in this document will enable us to guide national agencies and consumers about supports and services that are reasonable and necessary to live an ordinary life.

Image supplied courtesy of Cerebral Palsy Alliance

Having achieved major inroads thus far, we are excited about what the future holds for cerebral palsy, and what we can achieve with the framework of The Strategy. The Strategy unites voices advocating with and for people with cerebral palsy and their families in Australia and New Zealand to articulate priority goals and outcomes. Now is the time for change.

Image supplied courtesy of Cerebral Palsy Alliance

7.0 Method

Comprehensive independent community consultation was undertaken to inform the vision, mission, goals and priority objectives included in The Strategy, to create a document that reflects the voices and opinions of people with cerebral palsy, their families and professionals working in the field. Dyson Consulting undertook this consultation via focus groups, webinar, phone interviews and online consultative avenues.

A mixed-methods approach was used to enable an inclusive process that minimised participation barriers and catered for the varying needs and levels of engagement of different stakeholder groups. Online and phone consultations were the primary methods of consultation as these methods reduced or eliminated the participation barriers of:

- Requiring people to attend a forum at a specific place and time,
- Needing to arrange formal support to attend such forums.

A full draft of The Strategy was available for review during community consultation, as well as an executive summary and plain and easy English versions. Feedback was sought around the vision, mission, goal areas and measurability/success indicators of The Strategy. People with cerebral palsy and family members of people with cerebral palsy were also asked to provide feedback on life areas that were important to them and their satisfaction with a range of life areas. This allowed thematic analysis to ensure that areas where low satisfaction was endorsed were included as priorities in The Strategy.

139 people provided feedback via the independent community consultation, with the online survey being the most commonly used method for providing feedback:

- 98 people (70.5%) completed the online survey
- 16 people (11.5%) responded to the online submission questions
- 8 people (5.8%) or organisations uploaded a submission document online
- 11 people (7.9%) participated in a group consultation
- 6 people (4.3%) participated in key informant interviews

Of those who completed the online options (survey, submission questions or uploaded submission), 55% were people with cerebral palsy or family members or supporters of people with cerebral palsy; of these 23 (18.9%) were people with cerebral palsy, and 44 (36.1%) were family or supporters of someone with cerebral palsy.

Overall, feedback from community consultation was supportive of the vision, mission and goal areas of The Strategy. However, some areas, such as the vision, required refinement following community consultation. Furthermore, feedback identified a number of life areas that people with cerebral palsy and their family members reported low satisfaction in (see tables below). As such, these were included as priority areas within The Strategy.

The detailed community consultation report with full methodology and findings can be found as a separate Appendix online.

In addition to community consultation, The Strategy was presented at the Australasian Academy of Cerebral Palsy and Developmental Medicine Conference in Auckland 2018 where professionals provided feedback. Additional feedback was also sought from New Zealander representatives, including 15 people with cerebral palsy and their families, 8 researchers and 13 clinicians or professionals working in the field. An Expert Panel of 25 experts in the field (including people with cerebral palsy, family members and professionals) also helped shape The Strategy.

Image supplied courtesy of Cerebral Palsy Alliance

Table 6-8 Online survey – satisfaction (person with cerebral palsy)

Lived experience	Mean Rating (0 – 10)
Satisfaction with where you live	7.76
Satisfaction with who you live with	7.56
Satisfaction with the supports and assistance you receive with daily activities	7.38
Satisfaction with your access to appropriate health services	7.27
Satisfaction with your access to public and private transport	7.06
Satisfaction with how safe you feel	6.81
Satisfaction with your choice and control over the disability supports and assistance you receive	6.69
Satisfaction with your opportunities to have a social life	6.60
Satisfaction with therapists' understanding of CP and disability	6.38
Satisfaction with your opportunities to study, work, or volunteer, if you choose	6.13
Satisfaction with the accessibility of places you go or would like to go	6.13
Satisfaction with support workers' understanding of CP and disability	5.81
Satisfaction with feeling part of your community	5.69
Satisfaction with your access to appropriate therapy services	5.69
Satisfaction with doctors' understanding of CP and disability	5.13
Satisfaction with NDIA Planners/Early Childhood Early Intervention Partners knowledge and understanding of CP	4.60
Satisfaction with the general public's understanding of CP and disability	3.33

Table 6-9 Online survey – satisfaction (family member/supporter)

Lived experience	Mean Rating (0 – 10)
Satisfaction with who they live with	9.25
Satisfaction with where they live	8.56
Satisfaction with their access to appropriate health services	7.17
Satisfaction with support workers' understanding of CP and disability	6.63
Satisfaction with how safe they feel	6.51
Satisfaction with their access to public and private transport	5.83
Satisfaction with their opportunities to study, work, or volunteer, if they choose	5.72
Satisfaction with their feeling part of the community	5.72
Satisfaction with their access to appropriate therapy services	5.64
Satisfaction with their choice and control over the disability supports and assistance they receive	5.56
Satisfaction with their opportunities to have a social life	5.33
Satisfaction with the accessibility of places they go or would like to go	5.06

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8.0 Is the Search for ‘Cures’ a Reasonable and Appropriate Goal?

The notion of ‘cures’ for the different causes and associated impairments of cerebral palsy generated a range of responses throughout the development of The Strategy. This diversity of responses was evident within The Strategy Collaboration, the Expert Panel and feedback obtained through community consultation. The range of viewpoints on this topic are not new to those in the field.

Reasons put forward by a number of responders as to why ‘cures’ should not be included in the Australian and New Zealand Cerebral Palsy Strategy can be broadly summarised under three themes. First, as cerebral palsy is a lifelong condition diagnosed in infancy, some people with cerebral palsy and their families feel that having cerebral palsy is integral to their identity. Therefore, to suggest that ‘cures’ may be achieved insinuates something is wrong with them or that they are “less” than their typically developing peers and can be insulting. Second, the term ‘cures’ is often associated with disease. Cerebral palsy describes a cluster of motor conditions. As such, some people outlined that to use the term ‘cures’ could pathologise the condition and contribute to negative social stigma. Third, some people expressed concern that because they believe ‘cures’ are not achievable for cerebral palsy, the use of such a term may give families false hope of a “silver bullet” for reversing permanent disability, and thus it is not something for which we should aim.

> **“There seems to be so much emphasis on therapy. This obviously needs to continue because it’s helping people with CP live their lives on a daily basis however, if we REALLY want to improve the lives of people with CP, find out how to cure them.”**

> **“...we need to have a closer look towards finding more information about what causes cerebral palsy, how can we better treat CP, the potential preventative in medical treatment and finally one day a cure.”**

> **“I love the first part of the vision, ‘a world without CP’.”**

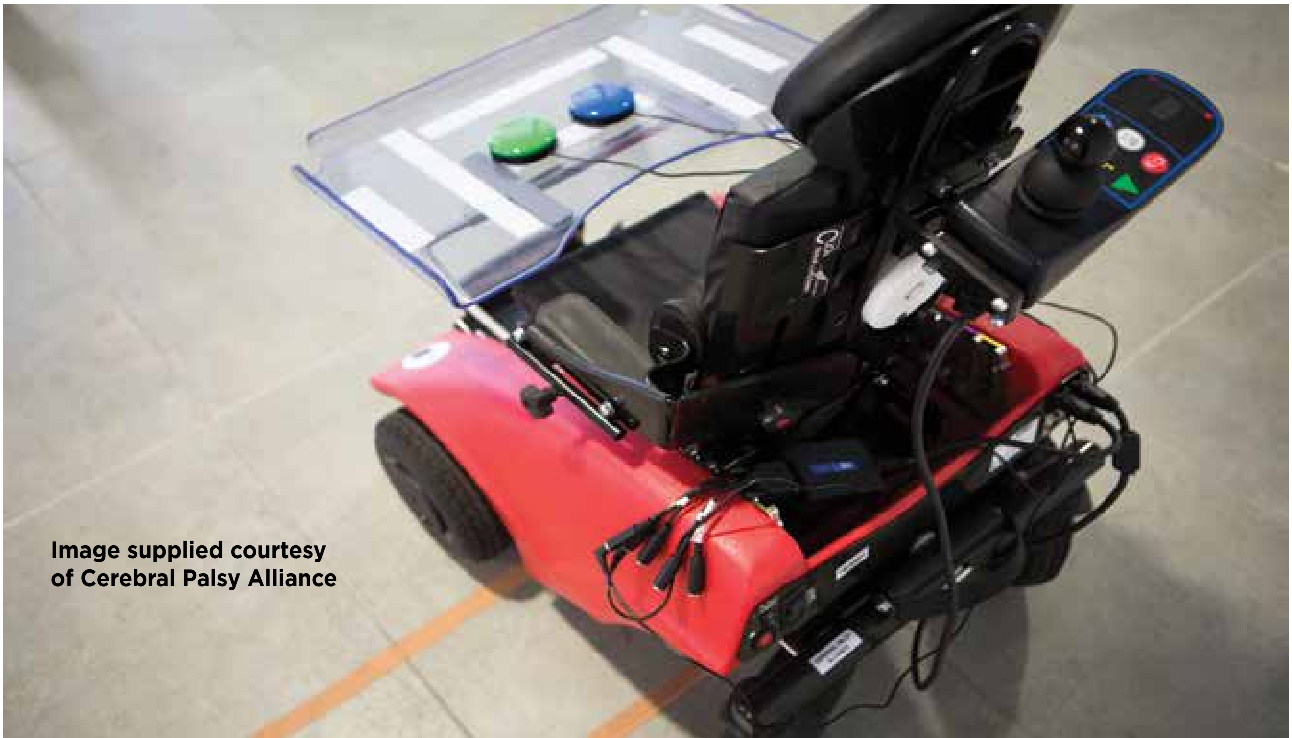

Image supplied courtesy of Cerebral Palsy Alliance

On the other hand, the concept of 'cures' was endorsed by the majority of people who participated in community consultation for The Strategy. Of those survey respondents who completed ratings in response to "How likely would you/your organisation be to publicly support the following goal statement? Cure and Prevention: To prevent future incidence of cerebral palsy and reduce the primary neuropathology of those currently living with cerebral palsy, with the goal of finding a cure," 81% endorsed the goal. Furthermore, when asked "How likely would you/your organisation be to publicly support the following vision statement", which included "Our ultimate vision is a world without cerebral palsy" an average score of 86% likelihood was obtained from respondents. Strong supporters for the inclusion of 'cures' in The Strategy expressed feelings that this is the most important aspect of The Strategy and that it is an integral body of work.

> **"Whilst finding a cure sounds great I feel this statement may be negative towards some people currently living with CP as they may not feel they need to be cured but rather supported to reach their potential."**

> **"The term cure is particularly problematic. I question whether a cure is realistic within the timeframe of The Strategy. The term cure is offensive to people with disability and has the potential to be quite damaging across the sector more broadly."**

> **"You can't cure CP."**

Whilst there may be many potential definitions of what a 'cure' or 'cures' are, for the purpose of The Strategy we define 'cures' as highly effective treatment/s for cerebral palsy that convey significant improvements in function and/or reduction of symptoms. A very simplistic example would be the now standard treatment for hypothyroidism, a simple to administer, once-daily oral tablet, which is not a 'cure' in the traditional sense, however leads to long-lasting, effective elimination of symptoms for the majority of people.

Whilst we acknowledge the diversity of viewpoints that exist with regards to the concept of 'cures' for cerebral palsy, we ultimately decided that it would be remiss of a comprehensive Australian and New Zealand Cerebral Palsy Strategy not to include 'cures' as one of the key goals based on the following reasoning:

- Overall, the inclusion of 'cures' was endorsed by the majority of respondents during community consultation.

- Although some may feel 'cures' are not in sight or achievable, if we do not strive towards achieving them, they may never be achieved. Research is underway and progress is currently being made in this area. As a result, 'cures' for some aetiologies of cerebral palsy, at certain ages, may be achieved sooner than expected. Moreover, by remaining open minded about future possibilities in the 'cures' field, new causal mechanisms, prevention strategies and interventions for cerebral palsy may be identified. An example of this is the concerted effort to search for a cure for cancer, which has led to numerous, highly effective treatments that enable people to "survive with cancer" long-term, with a high quality of life.

- From an ethical standpoint, it is important that scientifically valid 'cures' research is conducted in Australia and New Zealand under rigorous ethical oversight. Moreover, that these treatments are offered to participants free of charge. By fostering a thriving cerebral palsy research culture, individuals with cerebral palsy and their families/carers will not feel forced to seek out unproven treatments from unregulated "medical tourism" clinics, at great personal and financial risk.

- Just because something may be seem impossible, we should still strive to achieve it if it holds significant potential for individual and societal benefits. This is true for many areas relevant to cerebral palsy including 'cures', universal access and societal inclusion.

- Goals advocating for and supporting people with cerebral palsy and their families to reach their full potential and goals for 'cures' are not mutually exclusive. Both are needed.

- The Strategy has a comprehensive focus on advocating for and supporting those living with cerebral palsy and their families. We also need to include and reflect the views of those who see 'cures' as important for the field.

As a Collaboration we wish to acknowledge that all viewpoints on this topic are valid, and none are incorrect. It is not our intention to insult or undermine the identity of people living with cerebral palsy or their family members by including 'cures' in the Australian and New Zealand Cerebral Palsy Strategy. The Strategy aims to set the stage for focused efforts to improve the lived experiences of all, now and into the future.

Image supplied courtesy of Cerebral Palsy Alliance

9.0 Foundational Success Indicators

Through comprehensive community consultation, it became evident that in addition to goal-specific success indicators, the successful advancement of the field of cerebral palsy in Australia and New Zealand is dependent on developing a greater understanding of the state of the field across the two countries. This will enable us to better understand the impact of initiatives as they are implemented and the associated long-term costs and benefits. Thus, the following foundational success indicators are necessary in order to achieve the mission and vision of The Strategy, and to measure progress over time.

The Foundational Success Indicators for The Strategy are:

- Inclusion of appropriate cerebral palsy related variables in nationally collected data, such as through the Survey of Disability, Ageing and Carers, the Australian Institute of Family Studies and Census data, to enable the creation and utilisation of meta-data.
- Utilisation of NDIA, IF and Disability Support System Transformation data to better understand the supports and services received by people with cerebral palsy and how funding can be used most effectively and efficiently.
- Collection of common data elements across organisations providing services to people with cerebral palsy and their families to contribute towards meta-data.
- Continuity and long-term funding for State and National Cerebral Palsy Registers.
- Inclusion of participation, quality of life and economic evaluation in all cerebral palsy intervention and support research.
- Increase in the proportion of allocated research funding (federal, state, philanthropic and international funding) in line with the rate of occurrence and functional impact of cerebral palsy relative to other conditions.
- Inclusion of people with cerebral palsy, Aboriginal and Torres Strait Islander people and Māori peoples, and/or their families in co-designing all research and initiatives directly related to the field, embodying the slogan “Nothing About Us Without Us”. This will include the provision of financial resources to appropriately reimburse people for their time and remove disadvantage that might occur as a result of involvement, e.g. cover the cost of support worker attendance and travel, or the cost of carer’ fees for parents who need to put children in care to participate.

> **“Help the person move beyond their disability and to have control over their own life and to have an ordinary life.”**

10.0 Strategic Action Plan Inclusion and Engagement

To promote inclusion and active participation in all aspects of life, from an individual level to a community and societal level for people with cerebral palsy and their families

10.1 Goal Motivation

- Understanding life experiences and how these shape personal attributes such as motivation and self-determination will enable us to fully understand the long-term impacts of barriers on shaping an individual and their perspective.
- Inclusion and active participation have been demonstrated to have a range of positive impacts on multiple life areas.
- Deepening our understanding of the personal and environmental factors necessary to achieve a truly inclusive society and active participation will make it possible to develop initiatives to foster these attributes and eliminate barriers.
- Developing inclusive communities by educating and advocating for the benefits of engagement and active participation at all levels, from the individual level to the community and policy level, is crucial.
- Ensuring comprehensive and cohesive community structures and systems such as health, disability, education and aged care, that facilitate the inclusion of individuals with cerebral palsy, is necessary.
- Understanding life experiences of Indigenous peoples and the influence and importance of cultural values will facilitate finding the most effective strategies for promoting meaningful and sustainable participation.

10.2 Priority Objectives

1) To research participation, engagement and inclusion in relation to cerebral palsy, and develop ways to promote active participation and inclusion in all life areas across the life span. This includes but is not limited to: education, employment, physical activity, leisure/play, recreational activities, decision making, social inclusion, meaningful relationships, independence, community, family life, preventative health and disability services.

a) To understand the benefits and interactions of greater participation on all life areas, whilst ensuring the safety of those involved.

b) To identify determinants and barriers to participation.

c) To determine skills and personal attributes necessary to achieve desired participation outcomes, and how to best support individuals to develop these skills and attributes.

d) To understand the role of social and support frameworks in shaping engagement and participation to develop ways to overcome societal barriers to participation.

e) To understand the role of Indigenous peoples culture and history in shaping opportunities for participation, inclusion and engagement.

f) To understand the role of immigrant experiences and culture in shaping inclusion and engagement of immigrant peoples with cerebral palsy in Australia and New Zealand.

> **“The accessibility struggles I face on a daily basis as a wheelchair user is one of the greatest obstacles to my full immersion in every life experience.”**

2) To remove/overcome barriers and provide opportunities to optimise participation, inclusion and engagement in all life areas, for people with cerebral palsy and their families.	*a) To understand and address the relationship between cerebral palsy, poverty and other social determinants of health.* *b) To understand and address the relationship between complex communication needs and passive participation.* *c) To ensure all people with cerebral palsy have equitable access to high quality services and supports to participate fully in areas of their choice.* *d) To provide evidence-based services which encourage multi-level participation.* *e) To ensure education is inclusive and accessible for all people with cerebral palsy, so that they can actively participate and learn. To understand major determinants of participation in education, including but not limited to communication access.* *f) To review the extent to which employment is accessible and inclusive of people with cerebral palsy. To provide clear guidelines around what constitutes "reasonable" adjustments and accommodations in the workplace, so that people with cerebral palsy are provided with true equality of opportunity.* *g) To develop community initiatives and work collaboratively with appropriate bodies and organisations to promote and foster participation.* *h) To provide high quality support where it is currently lacking to assist people to participate to their fullest potential.* *i) To provide supports and services necessary to allow the person with cerebral palsy and their family members to participate and engage in all life areas.* *j) To understand the role of technology in participation. To provide access to technology that enhances participation.* *k) To engage with Indigenous communities to better understand the barriers that prevent inclusion and participation. This may include utilising Indigenous models of health, well-being and community engagement to support inclusion, engagement and participation of people with cerebral palsy and their families.*
3) To develop resources to measure and promote participation, inclusion and engagement of people with cerebral palsy and their families.	*a) To develop valid and reliable tools that are culturally appropriate to accurately measure participation and inclusion for Indigenous peoples.* *b) To identify and develop strategies to best promote a sense of motivation, self-efficacy and ownership over one's own participation.* *c) To educate people with cerebral palsy, their family/carers and the community on the benefits of inclusive participation.* *d) To develop resources to inform people with cerebral palsy and their families of participation opportunities available in their community.* *e) To advocate for the acceptance and inclusion of individuals with cerebral palsy in all activities and community.*

4) To examine the role of policy in shaping participation and inclusion. To advocate with people with cerebral palsy and their families for policy and societal improvements.	*a) To examine differences in engagement and quality of life of individuals with cerebral palsy internationally and identify the strengths and weaknesses of policies or social structures.* *b) To advocate for the rights of people with cerebral palsy to participate in all aspects of community. To advocate for accessible spaces and communities which allow for participation and inclusion.* *c) To determine what policies are needed to improve quality of life for families caring for people with cerebral palsy in Australia and New Zealand.* *d) To influence Government and policy makers to support the rights of individuals with cerebral palsy and help reduce negative societal influences on engagement and inclusion.* *e) To engage with Indigenous communities to identify potential societal inequalities or barriers and find the most effective strategies for promoting meaningful and sustainable participation for Aboriginal and Torres Strait Islander people and Māori peoples.* *f) To ensure that minority groups receive equitable opportunities for participation and inclusion. These groups may include people living rurally and remotely or socially and financially disadvantaged people.*

Image supplied courtesy of Cerebral Palsy Alliance

10.3 Success Indicators

- Development of an agreed suite of measurement tools to validly and reliably measure quality of life and participation-related-outcomes in the field of cerebral palsy across the life span.
- Inclusion of participation and engagement measures that are appropriate/relevant for Indigenous peoples with cerebral palsy. These may include cultural practices, family identity and linkages to the land.

> **“Quality of life for Indigenous people is inextricably linked to connections with family and country.”**

- A measurable increase in the proportion of people with cerebral achieving self-directed participation life goals, including but not limited to education, employment, independent living; relationships, sports, hobbies, leisure activities, travel and socialising.
- A measurable increase in the number of adults with cerebral palsy who are gainfully employed above the minimum wage.
- Mobility and complex communication needs of people with cerebral palsy to be better included in built environment and transport accessibility legislation (e.g. disabled bathrooms should have appropriate age change tables, automated doors, entrance access ways and hallway widths to meet the needs of people with customised powered wheelchairs, communication access for people who use high and low technology communication devices). Minimum access standards are to be built in rather than “bolted on” to design.
- Increase in the number of communication accessible spaces (hospitals, government buildings, local shops etc.) to ensure mutual understanding and enable active participation and inclusion, both in urban and rural areas (500%), as measured through Scope’s Communication Access initiative [56].
- Australian and New Zealand general public to have an accurate understanding of what cerebral palsy is and how to communicate with people with complex communication needs.
- Greater representation of people with cerebral palsy in print, screen and online media.

> **“I grew up never seeing anyone like me on screen or in print. I had no real role models … The fact that the strategy lists improving the exposure of people with CP in media as one of its main goals will literally change lives.”**

WHAT’S NEEDED?

- **Increased research funding**
- **Removal of barriers, increased corporate incentives, and the provision of appropriate supports to achieve participation goals**
- **Changes to accessibility standards legislation**
- **Funding initiatives to support businesses to undertake communication accessibility training and accreditation**
- **National media awareness campaigns around cerebral palsy and complex communication**

> **“Cerebral palsy doesn’t necessarily mean “I can’t do this.”**

Image supplied courtesy of Cara, South Australia

Image supplied courtesy of Cerebral Palsy Alliance

11.0 Strategic Action Plan GOAL: Health and Well-being

To improve health and well-being outcomes across the life span for people with cerebral palsy, to minimise impairment, maximise function and ensure life expectancy is in line with the broader population

11.1 Goal Motivation

- Recognising the diverse range of health and well-being-related needs across the life span of individuals with cerebral palsy is the first step necessary to improve health-related outcomes.
- Accessible and appropriate health services are required to help bridge the gap between health outcomes for individuals with cerebral palsy and the broader population.
- Developing competency and a sense of confidence amongst practitioners, allied health professionals, nursing staff and other health professionals in meeting the health-related needs of individuals with cerebral palsy will increase the accessibility and quality of health services.
- Understanding the impact of health and well-being on overall functioning, participation and quality of life will assist in advocating for the rights of individuals with cerebral palsy to have their health-related needs met.
- Promoting the place of general preventative medicine and sexual health care for people with cerebral palsy, with the individuals, family members, practitioners, therapists, support workers, and the broader community, whilst supporting the individual's right to freedom of choice, is necessary.
- Improving access to general health services and educating physicians so that individuals with cerebral palsy can have their health-related needs reviewed, managed and co-ordinated appropriately, is necessary.

> **"I have not been able to return to full time work since my son's diagnosis, given the number of medical appointments we have on a weekly and monthly basis."**

11.2 Priority Objectives

1) To increase knowledge of factors contributing to physical and mental health of people with cerebral palsy and their families.	*a) To understand determinants of physical and mental health for people with cerebral palsy across the life span.* *b) To understand the patterns of utilisation, costs and consequences of health services by people with cerebral palsy and their families.* *c) To identify the barriers for people with cerebral palsy utilising preventative health and health-promoting services.* *d) To respect the unique factors that contribute to Indigenous definition/s of well-being that will influence the dissemination of knowledge amongst these communities. These may include spiritual components and connection to the environment.*
2) To develop evidence-based strategies to optimise physical and mental health for people with cerebral palsy and their families.	*a) To determine the best early intervention approaches for preventing, identifying and minimizing impairments associated with cerebral palsy.* *b) To determine the most effective methods to manage secondary difficulties associated with cerebral palsy, including but not limited to pain, poor sleep, nutrition/feeding/eating and orthopaedic issues, to reduce their impact on functioning.* *c) To promote the development of personal attributes associated with positive mental health such as self-esteem, self-concept and self-efficacy.* *d) To understand the role of Indigenous culture and belief systems in both health service utilisation and provision.*
3) To provide accessible health care to people with cerebral palsy and their families.	*a) To integrate service provision to improve the process of transitioning between service sectors (e.g. paediatric to adult health systems, or disability to aged care funding systems).* *b) To address inequalities of access to preventative health services.* *c) To increase the sense of competency of health practitioners in meeting the health-related needs of people with cerebral palsy.* *d) To ensure the complex needs of people with cerebral palsy are met within the health system, e.g. ensuring hospitals are communication accessible, that practitioners are comfortable and confident talking to people using communication devices, that the person with cerebral palsy has a support person with them if they choose when discussing complex health needs.* *e) To provide access to high quality health care for all people with cerebral palsy and their families regardless of where they live.* *f) To ensure family members of people with cerebral palsy have access to supports and services to maintain their own physical and mental health. Here, 'family' is defined as anybody who supports the person living with cerebral palsy and as such may not be an immediate relative.*

4) To influence change to ensure that people with cerebral palsy and their families have their health-related needs met to the same standard as expected by all Australians and New Zealanders.	*a) To effect change to reduce the gap between general health outcomes for people with cerebral palsy and typically developing people.* *b) To influence societal change in the way that people with cerebral palsy are viewed in relation to their general health needs.* *c) To address societal stigmas and inform people with cerebral palsy, partners, carers and practitioners about their sexual health needs.* *d) To ensure people with cerebral palsy and their families, have choice and control over their own health-related needs.*

> **“Sexual opportunities are dismissed by most services. It HAS to be brought up, not just talked about but included as an option.”**

11.3 Success Indicators

- An increase in the number of Category 1 funded research projects examining, addressing and/or translating research targeting health outcomes for people with cerebral palsy and their families across the life span, antenatally to adulthood.
- Measurable increase in the proportion of people with cerebral palsy accessing preventative health screening/intervention e.g. immunisation, skin checks, breast screen, cervical screening test, prostate examination.
- Increased funding and access to targeted active surveillance and treatment of health-related needs associated with cerebral palsy across the life span (including early health intervention for babies and infants at risk of cerebral palsy from birth) e.g. musculoskeletal, pain, nutrition, sleep, hip surveillance, mental health, dental needs, neurological, respiratory and cardiac.
- Inclusion of evidence-based content about cerebral palsy - a life span approach - in nationally accredited medical, nursing and allied health training degrees, and ongoing professional development programs.

WHAT’S NEEDED?

- **Increased Category 1 research funding to improve health outcomes for people with cerebral palsy Removal of access barriers for essential preventative health screening**
- **Increased funding for active surveillance of health-related needs associated with cerebral palsy**
- **Changes to nationally accredited training degrees**

Image supplied courtesy of Cerebral Palsy Alliance

12.0 Strategic Action Plan GOAL: Intervention and Disability Support

To provide effective and timely evidence-based treatments and supports to ensure optimal outcomes for people with cerebral palsy and their families

12.1 Goal Motivation

- Continuously refining and implementing best available early detection methods will allow for the provision of early intervention and support, with the aim of reducing the severity of associated symptoms and optimising outcomes for people with cerebral palsy.
- Adopting a person-centred, integrated approach to intervention and disability support - recognising the fundamental place of families in the lives of children and adults with cerebral palsy - will provide the best possible outcomes for people with cerebral palsy.
- Ensuring that individuals have choice to access interventions and disability supports that best reflect their cultural and community practices, for example the choice to adopt a 'whānau-centred approach', 'shared care' or other traditional model, will enable best outcomes for people with cerebral palsy and should be a priority.
- Evaluation of the efficacy of interventions and disability supports should be considered in the context of functional and participation related goals. Multi-disciplinary and innovative approaches utilising advances in technology should be explored.
- An integrated approach to research and service provision will allow for ongoing development and evaluation of best available evidence-based interventions and supports.
- Translation of research, equipping health providers and individuals with cerebral palsy with the skills, knowledge and competency to provide or select appropriate intervention options, is paramount.

12.2 Priority Objectives

1) To develop optimal, evidence-based interventions, services and supports aimed at improving functional outcomes, enhanced participation and quality of life for people with cerebral palsy and their families.	*a) To examine the long-term outcomes of interventions and supports.* *b) To develop evidence-based treatments, compensatory strategies and support services effective in improving the functional ability and/or quality of life of people with cerebral palsy.* *c) To determine the optimal intensity, dosage and context of delivery of interventions and supports.* *d) To research the role of technological advances in intervention and provision of support for people with cerebral palsy to improve quality of life.* *e) To consider the pros/cons of providing a specific service, intervention, coaching or therapy on other areas of participation and quality of life.* *f) To understand interventions and supports in the context of the community/societal context in which they are delivered, for example, the difference between rural vs urban or home vs hospital settings. Furthermore, to consider the impact treatments may have on the wider community and/or resources.* *g) To investigate the therapeutic potential for alternative therapies and support mechanisms to address factors associated with cerebral palsy.* *h) To establish appropriate tools and research methodologies with which to evaluate efficacy of interventions and supports.* *i) To evaluate the cost effectiveness of potential support, intervention and service offerings.*

2) To understand the relationships among family, intervention, services and supports.	*a) To understand the role of parents, siblings, extended family, caregivers and communities in providing in-home therapy and support for people with cerebral palsy, acknowledging that social structures and relationships of Indigenous peoples will be different.* *b) To understand the impact of different forms of treatment, therapy and support on parents and siblings of people with cerebral palsy.* *c) To investigate the most effective methods of supporting parents and families in the context of complex disability and make these available.* *d) To understand the role of Indigenous culture as an enabler or barrier to accessing appropriate services.* *e) To understand the role of Indigenous concepts of health and community to ensure that extended family groups, for example whānau, are offered appropriate support services and guidance.*
3) To deliver high quality supports, interventions and services to people with cerebral palsy and their families.	*a) To develop and deliver timely, high-quality, evidence-based interventions, services and supports that optimise quality of life for infants, children, youth and adults with cerebral palsy and their families.* *b) To develop an efficient service model so that maximal services reach people with cerebral palsy and their families. To reduce the gap between interventions and supports that people with cerebral palsy and their families need, and what they actually receive.* *c) To ensure people living outside in regional, rural and remote areas have equitable access to high-quality evidence-based interventions, supports and services.* *d) To collaborate with the business sector to identify opportunities for making technology more accessible and viable to assist with intervention and supports.* *e) To reduce the time gap between when technology or supports are discovered/created, and when they become financially and physically available for individuals with cerebral palsy.* *f) To ensure people with cerebral palsy have access to supports necessary to achieve active participation, inclusion and engagement in education and employment.* *g) To increase the number and type of supported accommodation options available for people with cerebral palsy.* *h) To ensure people with cerebral palsy and their families have choice and control over the types of intervention and supports they receive.*

> **“The funds we ask for are not to test the limits of their budget but in order to ensure our very quality of life.”**

4) To disseminate intervention, service and support knowledge.	*a) To disseminate knowledge regarding efficacy of available treatments and supports to help guide people with cerebral palsy and their families to make informed decisions.* *b) To disseminate knowledge regarding efficacy of available interventions and supports to help guide funding bodies to make informed decisions about expected costs associated with meeting the treatment and support needs of individuals with cerebral palsy.* *c) To advise people with cerebral palsy with regards to changes in policy areas, and likely ramifications.* *d) To provide evidence-based advice to inform regulatory decisions around the efficacy, effectiveness and integrity of intervention options.* *e) To foster competency and ownership of professionals to treat and support adults with cerebral palsy with complex needs.*
5) To advocate for appropriate provision of service, supports and interventions for people with cerebral palsy and their families.	*a) To advocate for the provision of evidence-based interventions, services and supports.* *b) To empower individuals with cerebral palsy and their families to advocate for their rights to interventions, services and support.* *c) To develop an evidence base of case studies focusing on where transition to NDIS, IF and Disability Support System Transformation could be improved for individuals with cerebral palsy and ensure these are escalated in a timely manner to the correct levels of policy decision making.* *d) To ensure services, supports and interventions are appropriate and respectful of the cultural background of Aboriginal and Torres Strait Islander people and Māori peoples.* *e) To ensure services, supports and interventions are made available in a variety of languages*

Image supplied courtesy of Cerebral Palsy Alliance

12.3 Success Indicators

- A significant reduction in the time gap between diagnosis of "at risk" of cerebral palsy and the provision of first intervention.
- Establishment of a recognised working relationship between The Strategy Collaboration/Expert Panel and NDIA/IF/EIF/Disability Support System Transformation to inform what constitutes best available evidence around reasonable and necessary services, supports and interventions for people with cerebral palsy and their families.
- A proportional increase in the number of high-quality evidence-based interventions and disability supports available for people with cerebral palsy and their families who do not currently have equitable access, for example those people living outside major cities, socially and economically disadvantaged peoples, and people of culturally and linguistically diverse backgrounds.
- Increase in the number of services, supports and interventions available to Aboriginal and Torres Strait Islander people and Māori peoples that reflect their cultural beliefs and practices, as well as seeking to address pre-existing health inequalities in a measurable and sustainable way.
- Obtain data documenting the breakdown of national funding allocated for services, supports, and interventions both by severity level and across the life span to inform, help refine and advocate for necessary and optimal funding provisions for people with cerebral palsy.
- Young people with cerebral palsy receive the same level of support for all national exams (NAPLAN and HSC, SATs, National Certificate Educational Achievement) as has been provided throughout their schooling and higher education, without additional application processes.

> **"I really hope the strategy can succeed in making this [final exams at school] easier for students and their families because these exams are stressful enough without having to prove your disability and the fact you deserve a level playing field."**

WHAT'S NEEDED?

- **Policy changes to reduce funding eligibility restrictions**
- **A formal relationship between experts and funding decision makers**
- **Viable models for service provision for minority groups. Funding reflective of increased complexity**
- **Accurate data collection and transparency of funding allocation and provision**
- **Alignment of State and National education policy to reduce unnecessary bureaucracy and associated disadvantage.**

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Image supplied courtesy of Robert Halliday

13.0 Strategic Action Plan GOAL: Prevention and Cures

To continue to reduce and ultimately prevent the future occurrence of cerebral palsy and reduce the impact and severity of the damage to the brain for those born with and living with cerebral palsy, with the goal of finding cures

13.1 Goal Motivation

- Better understanding of the causal pathways of cerebral palsy is the first step necessary to developing effective preventative and/or curative strategies. This will enable and enhance investigations into new neuroprotective and neuroregenerative techniques, such as stem cells, which may hold the potential to provide therapeutic or curative outcomes for people with cerebral palsy.
- Furthermore, examining trends of cerebral palsy nationally and internationally, particularly in relation to antenatal and perinatal health policy and resources, will provide insight regarding aetiologies and efficacy of therapeutic techniques or care related initiatives.
- Identifying and advocating for viable funding options to continue to make leading medical advances and to reduce the occurrence and severity of cerebral palsy will be crucial to continue this work.
- Where possible, incorporate Indigenous understandings of treatments, cures and approaches to healthcare management. Examine how they can be incorporated into pre-existing approaches in a meaningful and sustainable way.

13.2 Priority Objectives

1) To better understand the causes of cerebral palsy and to collect population level data to examine changes in early identification, occurrence and prevalence over time.	*a) To map population level incidence and prevalence data nationally and internationally.* *b) To identify likely causes of cerebral palsy.* *c) To better understand the relationship between genomics and cerebral palsy.* *d) To understand policy and practices implemented internationally and how these influence early identification, occurrence and severity of cerebral palsy.*
2) To research new strategies to prevent cerebral palsy and reduce severity.	*a) To investigate advances in research and clinical practice for other conditions and examine any implication/relevance for the field of cerebral palsy.* *b) To identify potential neuroprotective interventions to reduce the frequency and/or severity of cerebral palsy.* *c) To identify potential neuroregenerative techniques to reduce the frequency and/or severity of cerebral palsy.* *d) To remain abreast of new discoveries and be flexible within a dynamic and fast-moving field.* *e) To conduct randomised control trials and other rigorous research methodology to examine neuroprotective/neuroregenerative interventions to ensure quality and consistency of evidence.* *f) To better understand the ethical and cultural considerations necessary in developing and providing preventative and restorative treatments.*

Image supplied courtesy
of Robert Halliday

> “...we need to have a closer look towards finding more information about what causes cerebral palsy, how can we better treat CP, the potential preventative in medical treatment and finally one day a cure.”

3) To ensure advances in research are rapidly translated into clinical practice.	*a) To translate advances of best practice in the prevention and/or severity reduction of cerebral palsy into mainstream practice.* *b) To advocate for practitioners to have access to and remain abreast of best available evidence on early identification, prevention and evidence-based interventions.* *c) To provide expert guidance to policy makers around the appropriateness and efficacy of policy initiatives in preventing and reducing the impacts of cerebral palsy.*
4) To advocate for further research examining the causes of cerebral palsy and potential preventative or curative strategies.	*a) To advocate for the importance of preventative and curative research through traditional and non-traditional funding sources.*
5) To have consumers involved in all aspects of research and intervention.	*a) To collaborate with individuals with cerebral palsy and their families to integrate their perspectives and priorities in all research and intervention.*

Image supplied courtesy of Emmanuel Angelicas, taken in Grace Centre for Newborn Intensive Care

Image supplied courtesy of JWP Photography

13.3 Success Indicators

- Greater levels of funding (federal, state, philanthropic and international) committed to understanding the causes of cerebral palsy and identifying new preventative and curative strategies aimed at reducing the incidence and impact of cerebral palsy.
- Implementation of best practice strategies for preventing cerebral palsy in at least 80% of major public hospitals across Australia and New Zealand (e.g. use of cooling and magnesium sulphate under appropriate circumstances).
- Earlier diagnosis of children with cerebral palsy before 12-months of age (from 52% to 60% diagnosed before 12-months).
- Reduction in the severity of cerebral palsy (from 1 in 3 children unable to 1 in 4 children unable to walk).

> **"Without early intervention, my experience of life with CP would be far harder."**

WHAT'S NEEDED?

- **Greater allocation of research funding, particularly funding novel approaches**
- **Greater awareness of cerebral palsy to enhance philanthropic funding**
- **Increased funding to public hospitals to buy equipment and provide ongoing professional development around best practice guidelines**
- **Early diagnostic clinics, networks and clear referral pathways for children at risk of cerebral palsy**

Image supplied courtesy of Paul De Sensi

Image supplied courtesy of Cerebral Palsy Alliance

Concluding Remarks

Cerebral palsy is the most common childhood physical disability and is a complex, lifelong condition. Despite this, cerebral palsy remains underfunded and under recognised in the political and social arena in Australia and New Zealand.

The Strategy is aligned with current legislation across Australia and New Zealand and represents a united voice, informed by lived experience, and families and professionals working in the field of cerebral palsy across Australia and New Zealand. The Strategy includes a range of short-, medium- and long-term priorities for the field of cerebral palsy, as well as success indicators achievable within the next five years. The Strategy establishes a pressing need for action, is a first step in the development of action plans across its priority areas and paves the way for a campaign to achieve its mission and vision.

Meeting the success indicators of The Strategy will provide significant benefits for individuals, families and communities, as well as convey social and economic benefits. Now is the time for action.

Image supplied courtesy of Gaela Kilgour

Australian and New Zealand Cerebral Palsy Strategy PLAN ON A PAGE

VISION:

Our vision is a society where every person with cerebral palsy, and their family, have a positive quality of life and are supported and empowered to have control over their own life choices. Our vision is also to prevent cerebral palsy, minimise its impact, improve outcomes and promote change that fosters inclusion.

MISSION:

The mission of the Australian and New Zealand Cerebral Palsy Strategy is to improve the health, function, participation and quality of life of individuals with cerebral palsy and their families, through advocating for the provision of optimal healthcare and disability support, excellence in research and enhanced community knowledge. This will help achieve a more inclusive and accessible society.

FOUNDATIONAL SUCCESS INDICATORS

- Inclusion of cerebral palsy related variables in nationally collected data.
- Better utilisation of National Disability Insurance Agency (NDIA), Individualised Funding (IF)/Enhanced Individualised Funding (EIF) and Disability Support System Transformation data to inform efficient use of funding for cerebral palsy.
- Collection of common cerebral palsy related data elements across service providers and researchers funded by federal government agencies.
- Continuity and long-term funding for State and National Cerebral Palsy Registers.
- Inclusion of participation, quality of life and economic evaluation in all intervention and support research.
- Increase in the proportion of allocated research funding in line with the rate of occurrence and functional impact of cerebral palsy relative to other conditions.
- Inclusion of people with cerebral palsy, Aboriginal and Torres Strait Islander people and Māori peoples, and/or their families in co-designing all research and initiatives directly related to the field.

GOAL: Inclusion and Engagement

Success Indicators

- Develop a suite of valid and reliable quality of life, engagement and participation measurement tools.
- A measurable increase in the proportion of people with cerebral palsy achieving self-directed participation life goals.
- A measurable increase in the number of adults with cerebral palsy who are gainfully employed above the minimum wage.
- Inclusion of mobility and complex communication needs of people with cerebral palsy in built environment and transport accessibility legislation.
- A 500% increase in the number of communication accessible spaces (hospitals, government buildings, local shops etc.) for people with cerebral palsy and their families, both in urban and rural areas.
- Increase in community understanding of cerebral palsy and how to communicate with people with complex communication needs.
- Increase in representation of people with cerebral palsy in print and screen media.

GOAL: Health and Well-being

Success Indicators

- Increase in the number of Category 1 funded research projects examining, addressing and/or translating research targeting improved health and well-being outcomes for people with cerebral palsy, from antenatal to adulthood.
- A measurable increase in the proportion of infants at risk, children, youth and people with cerebral palsy accessing preventative health screening/intervention.
- Increase in funding and access to targeted active surveillance and treatment of health and well-being-related needs associated with cerebral palsy across the life span.
- Inclusion of evidence-based content about cerebral palsy in nationally accredited training degrees and ongoing professional development programs.

GOAL: Intervention and Disability Support

Success Indicators

- A significant reduction in the time gap between diagnosis of “at risk” of cerebral palsy and the provision of first intervention.
- Establishment of a recognised working relationship between The Strategy Collaboration/Expert Panel and NDIA, IF/EIF and the Disability Support System Transformation.
- A proportional increase in the number of interventions and disability supports available for people who do not currently have equitable access for example those people living outside major cities, socially and economically disadvantaged peoples, and people of culturally and linguistically diverse backgrounds.
- Increase in the number of services, supports and interventions available to Aboriginal and Torres Strait Islander people and Māori peoples that reflect their cultural beliefs and practices.
- Obtain data documenting the breakdown of national funding allocated for services, supports, and interventions by severity levels and across the life span.
- A more streamlined approach to state and national education, so that people with cerebral palsy receive the same level of support for all national exams (NAPLAN and HSC, SATs, National Certificate Educational Achievement (NCEA) Part I, II and III) as has been provided throughout their schooling, without additional application processes.

GOAL: Prevention and Cures

Success Indicators

- Greater levels of funding committed to understanding the causes of cerebral palsy and identifying new preventative, curative and ameliorating strategies aimed at reducing the impact of cerebral palsy.
- Implementation of best practice strategies for preventing cerebral palsy in at least 80% of major public hospitals across Australia and New Zealand.
- Earlier diagnosis of children with cerebral palsy before 12-months of age (from 52% to 70% diagnosed before 12-months).
- Reduction in the severity of cerebral palsy (from 1 in 3 children unable to 1 in 4 children unable to walk).

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